

Practical Field Guide

for Community-based Human Rights Documentation

Based on Experiences from People Living with
HIV and Key Populations in Cambodia, China,
Myanmar, and Viet Nam

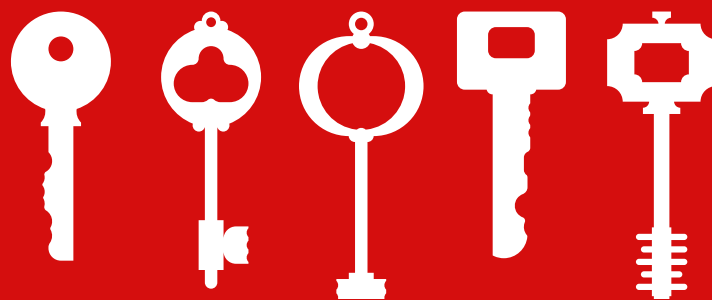


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Glossary

CBOs

Community based Organizations (CBOs) are civil society groups that are representative of a specific community and engaged in meeting human, educational, environmental or other needs of that community.

KP (Key Populations)

For HIV, World Health Organization (WHO) defines key populations as “defined groups who, due to specific higher-risk behaviors, are at increased risk of HIV irrespective of the epidemic type or local context. Also, they often have legal and social issues related to their behaviors that increase their vulnerability to HIV.” In the context of HIV, the World Health Organization has identified five key populations: 1) men who have sex with men, 2) people who inject drugs, 3) people in prisons and other closed settings, 4) sex workers and 5) transgender people. Key populations are important to the dynamics of HIV transmission. They also are essential partners in an effective response to the epidemic.

The term “key populations” comes from HIV. In the context of tuberculosis, Stop TB Partnership defines “key populations” as miners, prisoners, mobile populations, and people who use drugs; and “vulnerable populations” as rural poor, urban poor, and children under 5 years of age.

LGBT

This is the abbreviation for Lesbian, Gay, Bisexual, Transgender. It is an umbrella term for individuals and groups who identify as same-sex attracted and/or gender diverse. Another variation is LGBTIQQAA, which is more explicitly inclusive of Intersex, Queer, Questioning and Asexual individuals and communities as well as Allies. Many individuals and groups reject the term “LGBT” because of its western cultural heritage and the assumption that “LGBT” individuals and groups within this community experience discrimination, social inclusion or exclusion in the same way.

MSM

Men who have Sex with Men, which includes men who do not necessarily identify as “gay,” “homosexual,” or “bisexual.”

PLHIV	People Living with HIV
WHO	World Health Organization
WLHIV	Women living with HIV
UN:	United Nations

Introduction

In committing to the Sustainable Development Goal on health in 2015, UN member states resolved to "leave no one behind" in universal access to healthcare by 2030. However, in reality, many people are left behind. Every day across Asia, people living with HIV (PLHIV), key populations (KPs) such as sex workers, people who inject drugs, transgender people and men who have sex with men (MSM), as well as women and girls, ethnic minorities, migrants, refugees, children, prisoners, people with disabilities, and many other marginalized and vulnerable people experience human rights violations -- from the denial of access to essential health services and information, to police harassment and abuse.

These violations are rarely brought to light or addressed. In fact, marginalized and criminalized populations may not be aware of their human rights or that their rights have been violated. To get justice, you must have evidence.

This *Practical Field Guide for Community Based Human Rights Documentation* (the Guide) is a tool based on Asia Catalyst's longer, three-book curriculum: *Know It, Prove It, Change It: A Rights Curriculum for Grassroots Groups*. This shorter guide gives you the essentials you need to run a documentation project in the field. It also includes lessons learned from Asia Catalyst's Regional Rights Training project in 2015-16, which worked with eight community-based organizations from four countries to study the full curriculum, and then to document systematic violations of human rights in healthcare settings.

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

This series was created to help grassroots organizations in communities affected by HIV/AIDS to understand their basic rights, document rights abuses, and design and implement effective advocacy campaigns.

The series has three parts:

- ***Know It: The Rights Framework*** discusses international legal rights law and how it applies to people living with HIV/AIDS and other marginalized communities.
- ***Prove It: Documenting Rights Abuses*** 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 volume includes a manual, which describes the steps to take, and a trainer's supplement, which provides trainer instruction, lesson plans, sample exercises, and templates to use in a training workshop.

The *Know It, Prove It, Change It* series was developed by three organizations with extensive experience in rights documentation and advocacy: Thai AIDS Treatment Action Group (TTAG) in Bangkok, Thailand, Dongjen Centre for Human Rights Education and Action in Beijing, China, and Asia Catalyst in New York, USA.

We believe the best ways to fight rights abuses are to:

- Understand your basic rights
- Do research to document how these rights are violated, and,
- Plan and conduct an advocacy campaign to end the rights abuses.

Know It, Prove It, Change It draws on all three themes, but is primarily focused on conducting interviews to collect testimony from communities and document rights violations.

Asia Catalyst's Regional Rights Training Project

In 2015, Asia Catalyst used the *Know It, Prove It, Change It* series to work with eight CBOs from Cambodia, China, Myanmar and Viet Nam who wanted to integrate a rights-based approach to documenting HIV-related discrimination in healthcare settings.

The groups are:

- ARV Users Association (AUA) (Cambodia)
- Cambodian Community of Women living with HIV (CCW)
- Chengdu Tongle Health Counseling Service Center
- Consultation Centre for AIDS and Health Services (China)
- Aye Myanmar's Association (AMA) , Sex Workers Network
- National Network of People Living with HIV, Myanmar Positive Group (MPG)
- Kids Sun Group (KSG) (Viet Nam)
- Vietnam Youth Network For HIV and AIDS Prevention (VYPN)

Using the *Know It, Prove It, Change It* curriculum, the eight CBOs learned about the international human rights framework, human rights-based documentation skills, and how to develop effective advocacy strategies. They identified the most pressing issues of discrimination faced by people in their communities, who are people living with HIV and key populations, in healthcare settings. The eight groups used a participatory approach to doing the research, which means that evidence wasn't just collected *from* key populations, but *by* those same communities, and that community members played a role in all stages of the project.

This collective eighteen-month community-led research project resulted in findings and recommendations that were published in a comprehensive report, *First Do No Harm: Discrimination in Healthcare Settings against People living with HIV in Cambodia, China, Myanmar and Viet Nam* (Available for free download at: <http://asiacatalyst.org/resources/research/>). At the end of this guide, we share some of the advocacy work already underway, using this research.

The eight CBOs recommended that Asia Catalyst produce this short guide to use either as a refresher for people with human rights documentation experience, like themselves, or as a manual for people who are doing documentation for the first time. The groups shared some of their experiences to pass along in the guide.

Chapter one of this guide provides a crash course on principles and approaches to human rights based documentation. Chapters two discusses the importance of selecting the issue you or your organization wish to address before you begin your project. Chapter three to seven take you through the steps needed to complete your project, using a semi-structured interview as the method for documentation. Lastly, chapters eight and nine discuss how to wrap up your project and develop next steps. Throughout the Guide you will be provided with examples from the field, checklists, as well as tips on each

topic.

Each organization has its own internal culture and operates in a unique cultural and political climate. We therefore recommend adapting the tips in this guide to fit your organization's specific needs.

We have provided specific examples of community based organization (CBO) experiences in documenting rights violations in Cambodia, China, Myanmar and Viet Nam. They include challenges faced and lessons learned. If you have more specific questions, we recommend consulting the full curriculum online.

First Do No Harm: Discrimination in Healthcare Settings against People Living with HIV in Cambodia, China, Myanmar, and Viet Nam

Community-led research by CBOs representing sex workers, MSM, transgender people, and other people living with HIV, found widespread discrimination undermining an effective HIV response.

The findings highlight denial of services, segregated waiting areas, refusal to provide surgery, and discriminatory additional fees due to a person's HIV status.

1. Human rights documentation: The basics

For more, see the Introduction of Prove It: Documenting Rights Abuses

Why document human rights abuses? In order to end them. To analyze the causes of an abuse, to mobilize power, to hold abusers accountable, and make effective recommendations, you must have specific evidence that the abuse happened in the first place. When you begin on a documentation project, you need to have the end in mind: the end of the project is not the publication of the report, but the end of the abuse.

Before you start your project, consider:

- ✓ **Why document human rights violations?**
 - To provide justice for the victims of violations?
 - To advocate for a change of policies or practices?
 - Is there an opportunity to advocate for change?
- ✓ **Who will use the research, how and when?**
 - When you know how the research will be used, it is easier to focus on the specific information you need.
 - How much time do you have to do the research? What can you realistically get done in that time?
 - Plan to save enough time for writing, editing, or polishing the results.
 - Who do you need to influence? What kind of information will influence those people?
- ✓ **What do you need to prove happened (or failed to happen)?**
 - Do you need to get information about a large number of people, or gather more detailed information about a smaller number of people?
 - Can you get that information through interviews, questionnaires, field visits, video documentation or something else?
- ✓ **What are the risks?**
 - Could the research expose interviewers or interviewees to retaliation?
 - Could the research upset interviewees, or even cause them harm?
 - Are there other organizations you can refer interviewees to, in order to help them to meet their immediate needs?

There are many ways to gather evidence for use in advocacy. You may consider using quantitative documentation or qualitative documentation. Quantitative research seeks to test a hypothesis, and gathers data from a large number of people, often using surveys or other tools to gather numerical data. Qualitative documentation uses interviews and observation to analyze a problem. It emphasizes individual experiences and may require a small number of interviewees with extremely rich experiences. You can combine both approaches in one project: conduct focus group discussions with a community, carry out participatory observation, conduct surveys, gather relevant documents, and interview people to have them describe the violations in their own words.

This *Guide* focuses specifically on using interviews to collect details on individual incidents where rights were violated. Interviews and testimonies can provide powerful evidence to use in advocacy. Once we collect narratives, analyzing them can help us see patterns of violations and can shed light on underlying causes.

Whatever method you use, you must respect the dignity and confidentiality of the individuals whose rights have been violated.

In their words:

“ We explained the focus on right to health and HIV related violations in Myanmar to seventeen participants who were representatives of community networks. We also explained our objective was to deliver an official guidance letter to the Ministry of Health to reduce stigma and discrimination at public hospitals and to end double charging of people living with HIV. ”

– *CBO from Myanmar*

The basic principles of a human rights-based approach to documentation are:

- ✓ **Do No Harm**
 - Documentation should never cause harm to interviewees.
 - The physical, mental and emotional well-being of the interviewee is the single most important consideration.
 - The interviewees have the right to stop the interviews at any time and for any reason.
- ✓ **Be Transparent**
 - The interviewees should be fully informed and indicate that they understand the purpose of the documentation.
 - The interviewees should be fully aware of how the information they provide will be used, and what possible risks there are to them.
- ✓ **Make Security a Priority**
 - The interviewees should assess risks to themselves and to the interviewees and should take steps to manage all risks.
- ✓ **Ensure Confidentiality**
 - The interviewees must protect the confidentiality of the interviewees' identity and information at all stages of the project, including after the project ends.
- ✓ **Be Accurate**
 - Interviewees should maintain their objectivity and neutrality about all facts and claims.
 - Information provided by interviewees should be recorded and reported accurately.
 - All facts should be carefully checked.

In Asia Catalyst's Regional Rights Training, the CBO researchers used semi-structured interviews to document discrimination in healthcare settings. They worked together to agree on the questions they would ask, which they adapted to their own countries and contexts. Using semi-structured interviews allowed the CBOs to document detailed information on the violations, while also gaining an understanding of the interviewees' personal experience and to link the violations to the broader legal, political, social and cultural environment. They consulted with their communities to develop effective recommendations for actions.

This next section describes steps to take to identify the issues, consult with communities, choose the right interviewers, and complete a documentation project.

2. Identifying the issue

For more on how to identify a priority issue, see Chapter 1: Planning your project in Prove It: Documenting Rights Abuses

Community-based organizations provide services to communities and may also be involved in actively advocating for help for individuals, and for changes to policy and practice. With so many pressing community needs, CBOs usually have limited staff and resources to do the documentation work needed to build evidence for advocacy.

This makes it important to focus on a priority issue for advocacy, based on:

- Community needs
- The strengths and special expertise of the CBO
- Government commitments, including human rights commitments
- A practical opportunity to make a difference

A priority issue should be identified by **community members** who have noticed and shared experiences of violations that happened to them or to people they know. If other CBOs are working on the same issue, you might consider collaborating on strategy, documentation, and advocacy to maximize your impact.

Consulting directly with affected community members helps to clarify the focus of the project, and makes the project one that they own and have input into. If other CBOs are working on the same issue, you might consider collaborating on strategy, documentation, and advocacy to maximize your impact.

For more info on human rights, see *Chapter 1: HIV/AIDS, the rights framework in Know It: The Rights Framework*. For more on planning your research as part of an advocacy plan, see *Change It: Ending Rights Abuses*

Topics for discussion during the meeting:

- ✓ What are human rights?
- ✓ Why use the human rights framework?
- ✓ What is the right to health?
- ✓ What commitments has the government made but not implemented in practice?
- ✓ What national laws and policies are being violated?
- ✓ What is the difference between stigma and discrimination?
- ✓ What advocacy opportunities will there be in the near future, where we can share the results of our research?

Topics to address in planning your research:

- ✓ What human rights violations are occurring in the community?
- ✓ What are the possible causes?
- ✓ Is the violation an isolated incident, or does it happen often?
- ✓ Who is involved? (Victims, perpetrators, responsible government authorities etc.)?
- ✓ Are other CBOs also working to address the same issue? If so, how could we work together?
- ✓ What can our CBO contribute that is different or valuable?
- ✓ What are the potential risks to interviewees and interviewers?

Why consult with community?

- ✓ Establish a specific, shared advocacy goal.
- ✓ Build stronger support and commitment from communities; this will help facilitate access to interviewees, and start the foundation for a strong and sustained movement for policy change.
- ✓ Mobilize resources and ideas from different communities and networks to add value and depth to your project.

In their words:

“ Since we have been working on LGBT and HIV issues for more than ten years, we have encountered a lot of discrimination. We consulted two experts about the political and legal environment of people living with HIV and transgender people: one was a doctor in anthropology and the other a professor of law. They were both very experienced in issues of LGBT, sex workers and PLHIV. They shared their knowledge and experiences from both a personal and professional angle. ”

– CBO from China

Assessing and managing risk

Before starting on the project, the researchers must think seriously and discuss the potential risks of the project. 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 risk deserve respect.

Before starting on the project, think about who might be threatened by it. Are there organizations or individuals who benefit financially or professionally from the way things are right now? If you expose them to criticism, will they lose money or power? What power do they have to stop the project? Can they harm your organization, the interviewers, or the interviewees?

What has happened to other people who do the same kind of work?

There are some ways to minimize or avoid unnecessary risks. Here are a few, but in discussion with your colleagues and communities, you may think of others:

- *Anonymity* - You can change the names and identifying information of victims you interview, such as their age, hometown, occupation, and/or gender.
- *Be strategic about who the spokespeople are* – Media or power-holders may find some people more sympathetic than others. If you have diverse spokespeople for your project, you can choose the right speakers for different audiences.
- *Meet with organizations you will criticize early in the project* – If your project will be critical of an agency or group, you can bring allies inside that organization into the project early on, get their input, and show them how your research will help them to fulfill their own goals.
- *Build a strong base of support in your community* – If you are transparent and inclusive from the beginning of the project, and communicate frequently with your community about progress,

you can build a base of support among allies who know and value your work. If you are attacked or criticized, these allies will support you publicly and privately. Your attackers may find they are outnumbered and be forced to change their approach.

- *Keep reaching out to make new allies* – A larger organization can shelter a small CBO from attacks. Powerful people and institutions are often in competition with one another. If one is hostile to you, that may lead another organization to be open to what you have to say.

Tips for community consultation

- ✓ Draft an agenda, and share it with everyone for input.
- ✓ Consult with diverse groups within the community to understand the human rights issue from various perspectives, and go beyond those with whom you usually work.
- ✓ Agree on priority human rights issues faced by the community.
- ✓ Be prepared to listen to and learn from community members during the consultation process.
- ✓ Allow everyone to speak freely, allowing time for feedback; take notes of the feedback you receive to review later.
- ✓ Follow up and maintain contact with new partners.
- ✓ Keep the community informed about your plans and progress.
- ✓ Discuss the strengths of the communities and CBOs involved, and challenges you may face in the project.
- ✓ Discuss possible risks and develop a risk mitigation plan.
- ✓ Keep the group focused on making progress towards a clear, productive result.
- ✓ If you do not know the answer to a question, do say so honestly, and do follow up after the meeting.
- ✓ If you need to consult with participants who could limit an individual or organization's willingness to speak freely, meet with those people separately.
- ✓ Don't show any preference for one individual/organization's opinion over another.
- ✓ Don't let the meeting get off track with one person's agenda or opinions.
- ✓ Don't make any promises that cannot be kept.

3. Selecting Interviewers

To conduct great research, it is important to have the right interviewer. The survivor of a human rights violation may not be comfortable sharing their experiences with people they do not know or trust. They may fear a breach of confidentiality, stigma and rejection by the community, and retaliation by the abuser. It is crucial to select interviewers who can win the trust and confidence of community members.

Ideally, interviews should be conducted by people from within the community who know the relevant human rights issues, and are committed to the privacy and confidentiality of the information entrusted to them. Interviewers must have complete understanding of the project purpose and objectives. They should know why, where, and how the information will be used, and be aware of the possible impact on the interviewees (as well as on the interviewers).

Interviewers may come from your staff, volunteers, or your community networks. They should have the knowledge and skills needed to conduct interviews ethically, and collect data objectively. They should also have a basic awareness of human rights standards that need to be met for the project.

Many interviewers selected by the CBOs in the Regional Rights Training project were experienced in documentation work and had a deep understanding of their community's issues. They participated in additional specific trainings prior to conducting interviews. Training topics included:

- Documentation project goal and objectives.
- Ethical standards for documentation.
- Security issues for interviewers and interviewees.
- Cultural and logistical considerations.
- The interview guide, and interview techniques.

Tips for selecting interviewers

- ✓ Make sure that the interviewers can speak the local dialect and communicate easily with interviewees.
- ✓ Ensure that interviewers can relate comfortably to people of diverse socioeconomic and cultural backgrounds, and ensure that they do not have negative stereotypes about people they will interview.
- ✓ Select interviewers who can commit to the entire data collection period, to maintain consistency across all interviews.
- ✓ Ensure all interviewers are fully briefed about the project, its objectives, methodology, and advocacy goals, and can clearly communicate this information if asked.
- ✓ Train interviewers on the interview guide and on how to conduct interviews in a professional and sensitive manner.
- ✓ Be sensitive about gender considerations in selecting interviewers: some people may be more comfortable speaking to someone of the same gender.
- ✓ If you can, select individuals to act as note takers, so that the interviewer can focus on listening and connecting with the interviewee.
- ✓ Try to select the number of interviewers you will really need: too many interviewers could lead to inconsistencies in approach and data, and too few interviewees may not be able to finish the number of interviews you need.

In their words:

“ Next time, we will recruit more interviewers and make sure they all have a common training; to increase the quality of the interviews. ”

– *CBO from China*

“ We chose interviewers on the criteria that they should have [personally] experienced discrimination in healthcare settings. We also tried to have equal participation of different genders. ”

– *CBO from Myanmar*

“ The first learning for us is that the people involved should be fully committed. In our case, we had to replace two people at different stages [because the previous people quit]. ”

– *CBO from Myanmar*

“ We discussed how to build up trust with our interviewees and make them feel safe and comfortable during the interview. We also discussed how interviewers could use their own words to conduct in-depth interviews. ”

– *CBO from Cambodia*

“ We interviewed each other for practice and gave feedback for further interview strategies. ”

– *CBO from Myanmar*

4. Developing the Interview Guide

For more on interview skills, including coping with post-traumatic stress disorder, see Chapter 2, The Rights Interview, in Prove It: Documenting Rights Abuses.

Asking the right question is essential if you want to get powerful data to use for advocacy. An interview guide is simply a list of questions that help:

- Guide the interviewers and keep them focused on getting consistent information during interviews.
- Identify people who should be interviewed in more depth, based on their answers to the questions.

The CBOs that participated in Asia Catalyst's Regional Rights Training project chose to use an interview guide as part of their documentation of discrimination faced by PLHIV and key populations in healthcare settings.

The first step in developing an interview guide is to identify the kind of person you hope will answer the questions, also known as the respondent. To make sure the questions are focused and clear, you should think about the respondents' backgrounds, level of education, and knowledge of the issues.

The interview guide should be written clearly and simply.

For example, consider these two questions:

Example 1: Have you ever experienced a human rights violation at a hospital, clinic or other place where you receive healthcare?

Example 2: Have you ever had difficulty in receiving services at health care settings?

The first example is too vague. Not everyone knows what a “human rights violation” is, and it may mean different things to different people. Example 2 is a better question, because it focuses on the specific issue the researchers are studying.

It is also an open-ended question, which does not try to lead the respondent to give biased information.

Consider the following examples:

Example 1: Can you tell us about the negative experiences you faced when accessing health services?

Example 2: Can you tell us about your experiences in accessing health services?

The first example is biased and directs the respondent to find negative examples. The second example lets the respondent think freely about their experiences. It enables the respondent to analyze and narrate their story, free from the biases of the interviewer.

If your list or interview guide uses “yes or no” questions, it is best to include follow-up questions that provide detail on “who, what, where, when, why and how” in order to get more specifics on the issue. You may also want to use another list of questions to gather basic data, and then follow up to get those specifics with an in-person interview.

Remember this list is used as a guide for the interviewers, so they should be used with some flexibility. In human rights documentation, it is important to listen carefully to the story provided by the interviewee, which may sometimes

lead the interviewer in an unexpected direction. Each interviewee is different, and their responses to the same questions will also be different. Interviewers should be able to adapt to these differences, and make decisions on how to proceed with the interview, based on cues they get from the interviewee.

Some interviews may be stressful for the interviewee, especially if they have experienced physical abuse, mental abuse, and sexual violence. In these cases, the interview can cause harm, or “retraumatization” of the interviewee. If the interview involves discussions around these issues, the interviewer has an ethical responsibility to be prepared and ready to offer services to the interviewee. These could include referrals to medical care, psychological care, or legal support, for example.

In their words:

“ Some questions [on our interview guide] could be divided into subsets of questions. They should have been made more straightforward and specific for some persons, to make sure they could answer the questions. ”

– *CBO from China*

“ Some questions were too long and took more than 30 minutes [to answer], which is not easy for patients, as most of the PLHIV [we interviewed] are weak and could not talk a lot. ”

– *CBO from Cambodia*

“ In some interviews, we needed to skip some of the questions. If we re-wrote this interview guide, we would like to add instructions, such as, “If the answer is yes, go to question number x. If the answer is no, go to question number so and so. Those kind of instructions are needed in the interview guide. ”

– *CBO from Myanmar*

Consider the following when designing the interview guide:

- ✓ Have you consulted your staff and volunteers regarding question design, and incorporated their advice and experience?
- ✓ Are the questions appropriate for the respondents?
- ✓ Did you include an introduction to describe the research?
- ✓ Does each question have a clear purpose?
- ✓ Does the question order flow logically?
- ✓ Are the questions easy to understand and free of complicated words, abbreviations and jargon?
- ✓ Has the list of questions been tested or piloted to weed out errors and phrasing issues?
- ✓ How long will it take to answer the list of questions? Can the interview guide be made shorter?
- ✓ With these questions, can you get the information you need to prove the human rights violation you are investigating?
- ✓ Does the interview guide get information to the basic questions: who, what, where, when, why and how?
- ✓ Is the interviewer prepared to refer interviewees to medical care, psychological care, legal aid, or other support services if needed?

In their words:

“ We would focus the interview guide on [asking interviewees] to tell their experiences rather than asking for recommendations, as some interviewees did not understand when we asked for recommendations. ”

– *CBO from Myanmar*

“ Sometimes the interviewees could not find words to explain their feelings and experience, because of their low level of education. For example, when we asked what was the impact of discrimination and what are the consequences, it was difficult for them to understand. ”

– *CBO from Myanmar*

In their words:

“ Explaining what is meant by impact and consequences of the discrimination faced by PLHIV was difficult. Sometimes people did not think there was any impact or consequences because they did not think about it. So we found many different ways to explain what an “impact” could be and what “consequence” meant. ”

– *CBO from Myanmar*

Tips for improving the interview guide:

- ✓ Start with simple, easy questions, and build gradually to more challenging and open-ended questions.
- ✓ Include guiding instructions for interviewers to navigate around the list of questions. For example, indicate which questions can be skipped depending on certain responses.
- ✓ Ensure that sensitive questions that may have potential to trigger emotional and psychological stress are only broached once rapport has been established between interviewer and interviewee.
- ✓ Empower interviewers to deviate from a question if needed to obtain more clarification or details.
- ✓ Allow the interviewee time to ask the interviewers any questions.
- ✓ Do ensure there are follow-up questions to gather all necessary detail of an incident
- ✓ Do use language and vocabulary that is familiar to the interviewee
- ✓ Don't make the interview guide or the questions too long – this causes fatigue and loss of focus in the interviewee.
- ✓ Don't use terms that may be difficult for the interviewee to fully understand that or may be interpreted in multiple ways.
- ✓ Don't ask more than one question at a time.
- ✓ Avoid complex questions. Use follow-up questions to ask for more information.

5. Obtaining informed consent

For more detail on different types of informed consent, please refer to Chapter 2: The Rights Interview in Prove It: Documenting Rights Abuses. For a sample, see Annex A, Sample Informed Consent Form.

Asia Catalyst's approach to human rights documentation is a survivor-centered approach. This means that the needs and preferences of the person who survives a human rights violation should come first. Obtaining informed consent is at the heart of this approach. "Informed consent" means that each interviewee has full knowledge of the purpose of the interview and agrees to participate. An important element of informed consent is that the interviewee knows that they have the right to end the interview and decline the use of their information, at any stage of the project.

CBOs in the Regional Rights Training program used written consent forms. This is advisable whenever possible. If you use a written form, you should read the form and discuss it with interviewees before they sign. You may be working with people who cannot read and write very well and who may be embarrassed to admit that. Some people may feel anxious about signing their name to any formal document, especially if they wish to remain anonymous for security reasons.

However, oral informed consent can be given instead of a written form. If you are only using oral informed consent, it is recommended that you develop a standard informed consent form to guide the interviewer in the process.

Whether you use a form or use oral informed consent, begin with clear and accurate information about your organization, the purpose of the documentation project, and how the information will be used. We recommend stating clearly if the research will be published in print or online. You should also explain what information will remain confidential (such as names of

interviewees), and what will be used publicly. If there are any risks, these should be explained, as well as any steps your organization is taking to manage the risks.

The interviewee should understand that they can decline to be interviewed, that they can stop the interview at any point, and that they can require the interviewer to delete the information that the interviewee has provided, even after giving consent.

Four key elements of informed consent:

1. **Disclosure of research & risks:** The interviewer must clarify the purpose of the research, as well as any risks.
2. **Comprehension:** Interviewees should show that they understand the purpose of the research and the risks.
3. **Voluntariness:** Interviewees may agree to be part of the research without any pressure.
4. **Competence:** Interviewees must show that they have the physical, mental and legal capacity to understand risks and give consent.

Interview Preparation and Data Storage Tips

- ✓ Prepare an introduction and informed consent form.
- ✓ Print out enough copies of the informed consent form for ALL interviewees and get signature if they are providing written consent.
- ✓ Ensure your smartphone or audio recorder are charged and turned on, in order to record the informed consent and interview.
- ✓ Store the signed forms safely in a secure, locked location.

In their words:

- “ We developed the consent forms in two steps: first we developed it in standard Chinese language, and then we translated it again using colloquial words so that it was understandable to the community. ”
- *CBO from China*
- “ Sometimes participants did not want to sign the informed consent form, because they felt that by signing the document their names would be out in public. ”
- *CBOs from Myanmar*
- “ Before starting all interviews, we explained about the research, which was already mentioned also in the consent form. We explained how long the interview might take. We also explained to each interviewee how we were going to keep the records, and about the process of deletion of data. ”
- *CBO from Myanmar*
- “ We did not ask people to sign consent forms before, we only took verbal consent. I think it’s good to get the signature in a document, so we have proof that they have agreed to share their information. ”
- *CBO from Cambodia*
- “ Not all interviewees allowed us to record their voices. ”
- *CBO from Cambodia*

6. Selecting Interviewees

For more on the standards of evidence needed, see Chapter 3, Writing the Report, from Prove It: Documenting Rights Abuses.

Once you have prepared the interview questions, you will need to begin to find people to interview. This is often the biggest challenge: How to find interviewees?

Here are some possibilities:

- Interview a few people, who introduce you to other people who have had similar experiences. This is also known as “snowball sampling”, because like a snowball rolling down a hill, you gather more snow as you progress.
- Spend time socializing in a place where the kind of people you need to reach meet regularly (a harm reduction facility, a marketplace, a nightclub, a community center, a church or mosque); go to this place regularly and get to know the people there.
- Post a public request for interviewees somewhere where the people you need to reach will see it, and invite them to contact you if they want to talk (such as a social media site, a newsletter, or a bulletin board).
- Ask a person who is trusted by the people you need to interview to help to make introductions and arrange interviews (such as a community leader, or a peer outreach worker).

In some cases, the interviewers may need to use a variety of methods in order to get the quantity and quality of interviews needed.

For the research, you will also need to determine specific criteria for selection of interviewees. The criteria should ensure individual experiences collected are

representative of the community experiences, including diverse experiences within the community. CBOs the Regional Rights Training project interviewed people living with HIV, including women, men who have sex with men, transgender people and sex workers. The interviewees were identified from within the members of the CBOs, who then helped to find more interviewees from wider networks. Your project may want to take special steps to make sure you capture the experience of people who are not usually interviewed, such as people with disabilities, elderly people, or minority groups.

How many interviewees are enough to draw a conclusion? This will depend on what you need to prove. If you need to prove a specific incident took place, it is best if you have at least two or three eyewitnesses who describe seeing the same abuse. If you are trying to prove a widespread and systematic problem, such as denial of healthcare services by a hospital, then you need a larger

Tips to prepare for the interview for Interviewers and Project Managers

- ✓ **Develop a work plan** for interviewers that includes the number of interviews to be done, important deadlines, and logistical information needed to schedule the interviews (for example where will you conduct interviews? Does it require long travels etc).
- ✓ **Discuss safety and security concerns** and take steps to manage the risks prior to beginning interviews.
- ✓ **Allow enough time** to contact interviewees and make appointments; some interviews may take days or weeks to schedule.
- ✓ **Charge voice recorders** or smartphones and ensure there is a back-up plan in case they fail.
- ✓ **Carry printed informed consent agreements**, if these are being used. After the interview, store signed consent agreements and notes in a secure location, and avoid carrying the data around to other interviews.
- ✓ **Check that the interview space is noise-free**, as even small noises will be loud and disruptive on a recording.
- ✓ **Bring a pen and a notebook** in case the interviewee prefers not to have an audio recording of the interview, or in case the battery or recorder fail to work.
- ✓ **Keep about an hour for each interview** as some might be longer than others. It is not recommended to have interviews longer than an hour as that creates a burden on the interviewee.
- ✓ Give several opportunities for the interviewee to **ask any questions** they may have.
- ✓ **Thank the interviewee** for sharing their time and experiences.

number of cases to prove that the problem was widespread and taking place throughout the system, and not just a problem with one healthcare worker. Having documents, such as letters or receipts, can be valuable evidence in cases where it is difficult to get many interviews.

The quantity of evidence you need also varies depending on what you plan to use the evidence to do. If you want to present the evidence at a meeting or event, it may be best to have compelling stories from abuse survivors, even if the stories are from anonymous sources. If you plan to use the evidence to file a lawsuit, you will need detailed evidence, on the record, from one person who is willing to go public. Having the advocacy plan in mind from the beginning will shape the quantity and type of evidence gathered.

In their words:

“ Most of the interviews were in the office, in a partner CBO’s office or in a tea house. We chose the office because it’s safe and private. We chose the tea house for convenience of interviewees and to have a relatively private environment. ”

– *CBO from China*

“ At the end of the interview, we told them we are very proud of them for participating as an interviewee. We also told them that after we have the findings, we will share the findings with [the interviewees]. We plan to invite some of the interviewees to [an event where we will] share the findings. ”

– *CBO from Myanmar*

“ A lot of CBOs helped us with this research. Some participated as note takers. We explained about this work and how important it is. Some CBOs are already in our network for a long time, and we asked them to find us respondents. ”

– *CBO from Myanmar*

7. Establishing rapport

For more on building rapport and dealing with stress during interviews, see Chapter Two: The Rights Interview in Prove It: Documenting Rights Abuses.

In a survivor-centered approach to human rights documentation, interviews are guided conversations that an interviewer uses to gather valuable information about an individual's feelings and opinions about a specific experience of human rights violation. Interviews often provide greater detail and depth of information than a standard survey. Sometimes, the interviewer may not know what the interviewee will reveal once they begin to open up about the experience. In this approach, the relationship between the

In their words:

- “ We got the support from CBOs to meet the interviewees. The CBOs invited MSM to come to us. ”
– *CBO from Vietnam*
- “ [For our project, we found that] selection of interviewees should be done in a broader way (not only recommendations from volunteers); it should be a public recruitment over a longer period. ”
– *CBO from China*
- “ We contacted local leaders in target areas who were happy to provide support. The local leaders helped us with selecting note-takers and interviewees. When interviewers travelled to the field, they did not have to spend extra money for note takers' travel costs. [Local] volunteers also helped as organizers and supported us with other facilities such as an interview place. ”
– *CBO from Myanmar*

interviewer and the interviewee is important. Interviewers should try to establish rapport, or a feeling of kinship and trust, with interviewees.

Using open-ended questions could lead a great deal of information to be discussed in the interviews. The specific words the interviewee uses to describe her experience is also important, because they bring the experience to life. It is best to record the interview on an audio recorder or smartphone and transcribe it at a later stage. In this way, the interviewer is free to focus on really listening to the interviewee and on asking good questions. Some interviewees will be uncomfortable and less likely to speak if the interview is recorded. Remember that consent to record the conversation must be provided by the interviewee.

Choosing the right setting is important. The interviewers should identify a comfortable and safe venue where the interviewee can feel relaxed. Privacy, security and comfort of the interviewee is paramount. Some CBOs that participated in Regional Rights Training project used their offices for interviews. Other interviews were carried out in tea rooms, under trees, or in the homes of the interviewees. Each case will be different and space that feels safe to one individual may not feel safe or comfortable to another. Interviewers should discuss with the interviewees what they prefer.

It is also important for the interviewers to be safe and to take any needed steps to protect their security. This is an important discussion to have with interviewees prior to first interviews.

Once the interview begins, offering the interviewee something to eat and drink is one way to establish rapport. It can be helpful to find some things in common, for instance, by talking about children, the weather, the traffic, or other shared experiences.

Begin the interview with easy questions, and probe anything that seems

unclear. For example, "Can you explain exactly how that happened?" Listen carefully and do not interrupt when the interviewer is talking. If you notice confusing points, make a note of them and come back to them later to ensure they are clarified. If they are confusing for the interviewer, they will probably be confusing for other people as well.

Do not expect interviewees to be able to directly address your research question. Interviews should be structured around several focus questions, designed to cover the main aspects of your research questions. Interviewers should be careful of their body language and facial expressions, keeping them neutral and polite; expressions of surprise, judgmental comments, or emotional reactions may make the interviewees feel that they are being judged, and undermine the rapport. Questioning should also aim to encourage the interviewee to describe the events in their own words, not pressuring them to remember the events in a certain way.

Remember that the first principle is to "do no harm". If the interviewee becomes emotional or shows signs of distress, the interview should stop: this is a sign that the interview may be re-traumatizing the interviewee. Offer support by providing water, tissues or snacks. Remind the interviewee that they do not have to continue the interview; leave it up to them as to whether or not to continue, or if they just need to take a break. If the interviewee needs and wants it, the interviewer should be prepared to offer referrals to medical care, psychological care, or legal aid services. Unless the interviewer has been professionally trained to provide psychological aid to trauma survivors.

Keep the collected data (notes, consent forms, audio files) in a safe and secure place. Make sure everything is labeled with the date and time of the interview and destroy all recordings after the final research report is completed.

In their words:

“ We introduced ourselves by saying: we would like to learn how we could better help women living with HIV, particularly pregnant women affected by stigma and discrimination in healthcare settings. It is important for us to conduct this research because we want to be able to use the information that we gather from hundreds of people in order to design and deliver more services for pregnant and other women living with HIV. ”

– *CBO from Vietnam*

“ Some emotional things happened during the interview. Some wanted to stop interview for a while because they felt emotional. When they were crying, we stopped the interview for a while and gave water and tissue paper and waited till they calmed down and then continued. There was one interview that was nearly two hours. ”

– *CBO from Myanmar*

“ We asked them where would be most comfortable for them to talk. One guy, when we went to coffee shop, he felt uncomfortable talking about his experiences in the open coffee shop. So we moved to the office. ”

– *CBO from Vietnam*

8. After the Interview

Transcribing and Translation

After the interviews have been completed, interview responses should be transcribed from audio to written form. This can be time consuming and challenging, especially when the number of interviews conducted is high and staff capacity is limited. The eight CBOs in the Regional Rights Training project did a joint project that required translations for comparison across different contexts, and they found that translation took additional time.

One solution is to create an index of the audio recording, which lists the topics and the times when they were discussed. Using the index, someone who needs to can rewind or fast-forward the recording to find the specific topic.

Here is a sample index:

0:00 – 3:00	Interviewee gives informed consent.
0:300 – 05:30	Stigma in the healthcare clinic.
05:30 – 10:20	Healthcare worker used insulting language to sex workers.
10:20 – 15:00	Hospital overcharged for surgery.

It is best to transcribe immediately after the interview, if possible, in order to make an accurate transcription. For important statements and descriptions, it is best to use an exact transcription of direct speech, to keep the interviewee's voice and their specific choice of words. This will create more powerful testimony for use in advocacy.

In their words:

“ We needed more human resources to work on the transcription. ”

– *CBO from Cambodia*

“ After the interview, the interviewers should re-check the recording, including after translation, to make sure everything is [in the transcription]. We tried to follow-up with every interviewer to check if all the answers were noted down from the recording. ”

– *CBO from Myanmar*

“ All recordings were deleted. We used recorders and sometimes smartphones. Once it was transcribed and rechecked, everything was deleted. We did this because we had promised interviewees that the recordings of their voice would be deleted after transcription. [The transcriptions are saved in a locked, secure location] and the translated English versions were saved on a computer with a password, and also saved on a CD with password. We also had the informed consent forms locked separately from the transcribed files. ”

– *CBO from Myanmar*

Data Storage and Protection

Any information gathered from the survivors of rights violations is sensitive information, which was provided in confidence. It is the responsibility of the interviewers and all others involved in the project to ensure protection of the data, and to ensure that the information does not land in the hands of unauthorized personnel. It is also important to use the data strictly and only for the purposes for which the interviewees gave their consent. To protect the interviewees against retaliation, information that is made public should be anonymized.

Tips for securing collected data

- ✓ Where is the data stored? Limit the number of people who know where it is and who have access to it.
- ✓ Give codes to each interview to anonymize the information, so that it cannot be traced back to the interviewee. Keep any list of the names of interviewees separate from the transcriptions and records of the interviews.
- ✓ Create a system for labeling and storing data so that it can be easily retrievable when you need it.
- ✓ Consider how long you need to store the raw data and interview recordings. Have a plan to destroy the original data after the purpose of the collection is complete.
- ✓ Consider different scenarios in which the data can be misplaced, stolen or lost. Have plans in place to prevent loss or theft of data in each of the scenarios.
- ✓ Ensure back-up of the data – and make sure the back-up is NOT in the same place as the original data.

9. Using the documentation: Next steps

The purpose of doing human rights documentation is not to publish a report. It is to end the rights abuses. The documentation can be used in many ways in advocacy, depending on your objectives and the opportunities. The same documentation may be used repeatedly over a year or two years: to inform and mobilize the community, to ensure survivors can access support and services, for litigation, or inform national- and international-level policy advocacy that can end the abuses.

We recommend developing an advocacy strategy for your research. *Change It: Ending Rights Abuses* explains the steps to take to develop a human rights advocacy strategy, learn advocacy tactics, mobilize media and the community, and use research to create positive change.

A first step should be to gather members and organizations from your community, just as you did in the beginning of the project, to provide an informal report-back on the data collection and preliminary analysis. You may invite them to learn about the project, thank them if they were involved, and engage them in analyzing the findings, to further improve your understanding and develop recommendations that reflect the needs of the wider community. Sharing experiences and knowledge from human rights documentation and advocacy projects can strengthen community solidarity. It can also help to build their capacity to minimize or prevent violations, to hold perpetrators accountable, or to achieve other forms of justice.

Regional Rights Training Project: Results and Impact

The eight CBOs from Cambodia, China, Myanmar and Viet Nam did joint research into human rights violations against people living with HIV in healthcare settings. Asia Catalyst supported the groups to coordinate the documentation and publish a research report, [*First Do No Harm: Discrimination in Healthcare Settings Against People Living with HIV in Cambodia, China, Myanmar and Vietnam*](#). The report was published online in March 2016.

Working together over 18 months, the CBOs conducted 202 interviews in all four countries. Their research found widespread stigma and discrimination in healthcare settings, and abuses including denial of healthcare, forced sterilization, segregated waiting or treatment areas, and subtle changes of treatment from surgery to oral or topical treatment instead. They found abuses against people living with HIV and key populations by healthcare workers.

The CBOs collaborated to develop a set of specific recommendations based on the research. Asia Catalyst and the CBOs widely disseminated the report at national and international media, meetings and to UN and government agencies. They also shared the research with other CBOs who work on related issues, to coordinate advocacy.

Here are examples of how these CBOs are using documentation and advocacy to promote discrimination-free healthcare services for their communities.

I. Raising Awareness on discrimination faced by MSM living with HIV in healthcare settings via Social Media in China

Chengdu Tongle Health Counseling Service Center in Chengdu, China organizes large-scale campaigns for public education on HIV, conducts HIV-related training for healthcare workers, and provides HIV testing and psychological support for community members.

As part of their advocacy plan and to raise awareness, Chengdu Tongle launched a social media platform for community members to actively participate in discussions, share information and report on discriminatory experiences. Through the research and social media outreach, Chengdu Tongle found that MSM living with HIV were not only being denied access to surgery services due to their HIV status, but also that many MSM did not recognize this as a violation of their rights. To address the lack of understanding among the communities, the organization conducted a rights training for ten volunteers.

Following the training, Chengdu Tongle set up a social media space where they shared information on MSM health and rights. The ten trained volunteers also shared cases of discrimination, while providing peer support. The volunteers summarized the findings of the documentation work, such as refusal of surgery services to MSM living with HIV. This encouraged dialogue within the community on this prevalent issue.

This space is now increasingly being used by the community as a safe place to discuss and share their experiences, information, and support, and to report and act on cases of discrimination.

II. Creating Space for Dialogue between Community and Stakeholders in Cambodia

ARV Users Association (AUA) and the Cambodian Community of Women Living with HIV (CCW) are two Cambodian CBOs that collaborated in documenting discrimination faced by women living with HIV in accessing pregnancy related services. As part of their advocacy plan, the two groups organized discussion in two provinces in Cambodia.

The discussions took place in Thbong Khmom province and Battambang province, and were held in cooperation with the National AIDS Authority

(NAA) and Provincial Health Department of the Ministry of Health. The groups organized discussions between people living with HIV, healthcare providers and policy makers to share their research findings. The discussions centered on the rights of PLHIV and the importance of access to health services.

PLHIV and key population representatives had a chance to share experiences of discrimination they faced at healthcare settings, while healthcare providers shared their experience of working with PLHIV and key populations. During these discussions, participants stated that they found the discussion significantly improved their understanding of the issues faced by PLHIV, MSM and Entertainment Workers. Local authorities (governors, commune leaders and police officials) committed to strengthening their management, and to paying additional attention to the needs of PLHIV and key populations.

The CBOs also used their research findings to conduct workshops on human rights violations and discrimination in healthcare settings for healthcare providers, partner NGOs, women living with HIV, and key populations in Siem Reap and Kampot. 74 participants attended these workshops.

AUA has successfully used their human rights documentation project into a series of ongoing, constructive dialogues between community members and health service providers. AUA plans to continue to conduct PLHIV rights discussions in other provinces of Cambodia. They also plan to organize group discussions between PLHIV and relevant authorities to end stigma and discrimination in employment, and in this way to ultimately reduce poverty among PLHIV.

III. Educating communities: Training women living with HIV in Viet Nam

As part of their advocacy plan, on World AIDS day, Kids Sun Group (KSG) organized a sharing workshop for WLHIV on Sexual and Reproductive Health Rights and soft skills needed for negotiating with healthcare workers.

30 WLHIV between the ages of 25 - 40 years, from four districts, attended the event, which created a demand for further training. KSG also created a group email list for the training participants to receive more information on sexual and reproductive health rights, prevention of mother-to-child transmission, and related law and policy information.

Following this, KSG organized a coordination meeting between CBOs, WLHIV and healthcare providers at which they shared the findings from the research and some specific discrimination stories. The meeting brought together 35 participants, including 12 healthcare workers, five medical journalists, five WLHIV and 13 volunteers.

Conclusion

This guide was developed in the weeks after the publication of the report, so advocacy strategies are still being implemented. However, even at this early stage, CBOs from the Regional Rights Training project have shown how human rights documentation led by communities can become a valuable tool for opening up channels for advocacy and discussion between people living with HIV, key populations, and officials.

Asia Catalyst hopes you will use this guide to keep the learning going, and help to build collective knowledge in your community and across your networks by sharing your documentation experiences with your colleagues. We would love to have your feedback on the usefulness of the guide, and how it has been used by CBOs to bring abuses to light and advocate for their end.

About Asia Catalyst

Asia Catalyst builds strong civil society and advances the right to health for marginalized groups in Asia. We train CBOs to meet high standards of effective and democratic governance within their organizations, establish a stable foundation for future growth, and conduct rigorous human rights documentation research and advocacy. We are an independent organization that places the needs of marginalized communities at the center of national, regional, and international policy-making.

Across Asia, marginalized communities face serious challenges in accessing and protecting a broad array of human rights. They are often without the skills or resources to address systemic or acute abuses. Asia Catalyst addresses these challenges through rigorous and tailored capacity building, research, and advocacy support to emerging civil society leaders and organizations in the region. We believe that CBOs have an invaluable understanding of the needs and circumstances of the groups they represent and, with the right support and resources, are best positioned to advocate for their own rights.

For more information, please contact: info@asiacatalyst.org

ANNEX A: Sample Informed Consent Form

(Before beginning the interview, the interviewer should read out this form, and leave one copy of the form with each interviewee).

This Informed Consent Agreement provides information related to the _____ (title of research project) research project, to be conducted by _____ (organization).

Please read this consent form carefully and ask as many questions as you like before you decide whether you want to participate in this research study. You can ask questions at any time before, during or after your participation. Contact information appears at the bottom of this agreement.

Purpose (This section outlines the purpose of the research)

To claim rights through legal means is an effective way to realize the equal rights of people living with HIV/AIDS and to address discrimination. Advocacy through legal means with the aim of removing discrimination, promotion of rule of law and promotion of social responsibility, can promote the well-being of people living with HIV/AIDS. This research project includes a survey of existing laws and policies and how laws are implemented in practice, as well as analysis of major causes of discrimination against people living with HIV/AIDS. Based on this research, we aim to provide specific recommendations to address the problem.

Procedures

As part of this research, we would like to interview you. Depending on our conversation, the estimated time for the interview is between 30 and 60 minutes. There will be some sensitive questions in the interview. We

hope you can participate in the whole interview and give us as much information as possible. Your willingness to share your experience is the most important resource in our research. If any questions make you confused or uncomfortable, or if you prefer not to answer, you have the right to refuse to answer them. During the interview, you can stop the interviewer to ask questions at any time, or to take a break. You always have the right to stop the interview. In addition, you have the right to request that we remove information from our records after you have provided it. There will not be any possible negative impact on you if you decide to stop the interview.

Confidentiality

All information we obtain during our interview with you will be treated with confidentiality. We will not use your real name in our published report or book. Only the researchers participating in the research will have access to your personal information. Any names used during your interview (yours and those of any individuals you mention during the interview) will be replaced with false names.

The interview will be recoded so that we can preserve the content of the interview, but we will not use your voice recording for any public purpose. The recording will be kept in a secure location. Your words will be transcribed and used as original material in the final report and in related academic works but always with the substitution of a pseudonym to avoid identifying you personally.

Possible Benefit

You will not receive any payment or direct benefit from our research. However, your participation may contribute to our efforts to combat HIV/AIDS-related discrimination in the healthcare system.

Statement by the researcher

I have provided a copy of this Informed Consent Agreement to the interviewee and have received her/his consent to proceed with the interview. I will respect and execute the rights described in this policy. I promise to guard the confidentiality of all written notes and recordings from this interview, including this form. The information gathered in this interview will be used in the following circumstances and in accordance with the assurances provided to the interviewee in this Informed Consent Agreement: (1) in the database of this research; (2) in our initial internal reports and other periodic reports; (3) in the final report; (4) in team meeting materials; (5) in academic papers and books; and (6) in other related academic research and policy survey.

Signed:**Date:**

Authorization by Interviewee

I have read the Informed Consent Agreement provided by this researcher and have received satisfactory answers to my questions about informed consent. I volunteer to participate in the research. I authorize the researcher to (select one):

Take notes and record my voice

Take notes only but not record my voice

I agree that the researcher can process and use this material according to this Informed Consent Agreement, and certify that I have received a copy of this agreement.

Signed:

Date:

Make sure to include contact information for the organization leading the documentation project on your consent form