

HUMAN RIGHTS DOCUMENTATION GUIDE

SPEAKER NOTES

INFORMED CONSENT

Hello and welcome to PILPG's module on informed consent. My name is Dr. Margaret deGuzman and today, I will be discussing how to employ this principle throughout a human rights documentation mission. Informed Consent is one of four key principles for conducting an ethical human rights documentation mission. The other 3 principles are:

- Do No Harm;
- Ensuring Confidentiality; and
- Mitigating Retraumatization

Informed consent is agreement to participate based on a complete understanding of the process and of the potential benefits and adverse consequences of such participation.

Complete understanding includes comprehension of:

- The nature of the process,
- Why the information is being sought,
- How the information will be used;
- The participant's right to refuse to participate;
- The potential risks and benefits of participation; and
- That consent is given voluntarily without coercion by others.

All victims and witnesses must give their informed consent prior to any engagement with documenters, including being interviewed, externally examined, photographed, having their information recorded, being referred to any support services, or having their information and contact details shared with third parties.

Informed consent must be obtained before the first engagement with documenters, and must be re-affirmed before any subsequent engagements. Additionally, informed consent should be reaffirmed at the conclusion of the interview.

Obtaining informed consent is an ethical obligation for anyone gathering information about serious human rights abuses.

Informed consent helps to ensure that victims and witnesses maintain control over their own experiences, that their rights are respected, and that any harm to them is minimized.

Failure to obtain informed consent may result in evidence not being accepted in legal proceedings.

- Identity of documenter and organization
 - Documenters should identify themselves and the organizations for which they work. They should explain the role of the organization in the documentation effort, as well as the role of any affiliated organizations such as a government, religious group, legal body, or international organization.
- Purpose of Documentation
 - Documenters should explain the purposes of the documentation effort, including how the information may be used in the future, for instance in organization reports, investigation or judicial processes, advocacy materials, or United Nations submissions.
 - They should inform participants that in the event anyone seeks to use information obtained in a different way from the original stated purpose of the documentation mission, updated informed consent will be obtained.
 - Documenters should also explain the process that will be used to gather information.
- Access to Information
 - Documents should explain to prospective participants who will have access to the information (including any third parties), as well as how the information will be stored.
- Potential Risks and Benefits of Participation
 - Documenters should explain any potential risks and benefits of participation.
 - They should emphasize that no benefits are guaranteed. For instance, if information is being gathered for use in a possible future legal proceeding, documenters should be clear that the proceeding may not take place or may not yield the desired result.
- Voluntariness
 - Documenters should strive to create an environment in which prospective participants feel comfortable asking questions, expressing concerns, and declining to participate.

- Documenters should ensure that prospective participants understand the information conveyed, that they have a right to decline to participate and to stop participating at any time, and that any consent must be entirely voluntary. One way to do this is to ask prospective participants to repeat this information back to the documenter before giving their consent to participate.
- Follow-up Information
 - Participants should be provided information about how to contact the documenter or the organization after the interview to ask any questions they may have regarding the use of the information, changes to the information they submitted, or withdrawal of consent.
- The best way of recording informed consent is to provide the prospective participant with a pre-drafted consent form for their review and signature.
 - This form should be written in a language the prospective participant understands. If they do not read, the document should be read to them and they should be provided an opportunity to ask questions about it.
- If a pre-drafted form is not available, a handwritten form can be created or a recording of informed consent can be made.
- Whatever document or recording is used must contain all key pieces of information on the checklist including:
 - The **purpose** and **content** of the information collection;
 - **The** procedures to be followed, including any potential disclosure of information to third parties; and
 - The right of the interviewee to **decline** or **refuse** to answer any question and/or revoke their consent at any time.
- When the documenter is confident the participant is ready to provide informed consent, the form should be signed, or, for participants who do not write, a thumb print can be used. The form should also be dated.

Regardless of how informed consent is recorded, the participant must be identified in some way. This can mean recording their name or, if the interviewee wishes to not be identified by name, a pseudonym or code can be used.

When documenters seek to obtain information from a minor, they must first obtain informed consent from the minor's parent or guardian. Once a parent or guardian provides consent, informed consent must also be obtained from the minor. All communication with minors should take into account their age, specific needs and level of understanding.

These are some of the issues to consider in adhering to the principle of informed consent. Remember, this principle must be respected at every stage of the process.

This concludes the module on informed consent. Thank you!