

# **WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies**



**World Health  
Organization**

# 5. Confidentiality

**Recommendation. The confidentiality of individuals who provide information on sexual violence must be protected at all times.**

## **Good practice: maintaining confidentiality**

When using focus groups or other group discussions as a means of collecting information about sexual violence, participants should be briefed about the need for confidentiality and the safeguards that will be adopted to protect their privacy. This is best done at the beginning of the meeting, repeated at the end, and should include acknowledgement that confidentiality is the responsibility of all group members.

Focus group participants should be instructed not to share personal experiences on sensitive issues, but rather to present the experience of unnamed others or impressions of trends in the community. Confidentiality should relate to both nature of the discussion (i.e. what was discussed) as well as to what was said and who was present.

Preserving the confidentiality of personal information is one of the fundamental principles governing the collection of data about individuals. Every person has a right to privacy, and this right imposes an obligation on those collecting personal data to keep this information confidential.

Any personal information that an individual discloses in an information collection exercise should be considered to be confidential. This means that there is an implicit understanding that the disclosed information will not be shared with others, unless the person concerned gives explicit and informed consent to do so (see Recommendation 6).

In the context of sexual violence in emergencies, the stakes can be very high. In such circumstances, a breach of confidentiality does not only represent a breach of ethics, but can also lead to harm for the survivor and for the community. Therefore, anyone asking someone to disclose information bears a responsibility to safeguard that information.

The requirement to maintain confidentiality governs not only how the data are *collected* (e.g. private space in which to conduct an interview), but also how the data are *stored* (e.g. without names and other identifiers) and how, if at all, the data are *shared*.

- 5.1 Standard operating procedures (SOPs) which clearly describe the arrangements for maintaining confidentiality should be developed as part of the planning phase of the information gathering activity.
- 5.2 Confidentiality SOPs should specify the steps that should be taken in the event of a breach of confidentiality and also the consequences. Penalties for breaches of confidentiality should be enforced.
- 5.3 In the case of children, if immediate protection needs become apparent, it may not be possible to honour confidentiality and also serve the best interests of the child. Further guidance and advice on this issue should be sought from child rights, ethics or protection experts when establishing SOPs for confidentiality (see also section 5.13 and Recommendation no. 8).
- 5.4 All individuals involved in data collection, documentation and/or research relating to sexual violence should receive training in the need for strict confidentiality (see Recommendation no. 7). As part of this training, team members should be afforded the opportunity to discuss practical applications of confidentiality principles in the setting in which they will be working. All

team members should understand, agree to, and sign confidentiality agreements.

- 5.5 It is especially important to highlight confidentiality and safety issues in settings where the interviewers and other team members are drawn from the community or are living within the community that is part of the planned investigation. Under these circumstances, training programmes should stress the challenges local staff are likely to face in maintaining confidentiality when they interact with the community on a day-to-day basis, and provide strategies for addressing these concerns (see Recommendation no. 7). Careful consideration should be given as to whether interviewers should work within their own communities.
- 5.6 The names of survivors, interviewees and/or translators should not be used on forms or case records, or in documents or other types of written materials generated as part of the investigation (see also section 4.2). If, for whatever reason, follow up is required, a system of case numbers could be implemented. The index linking names with case numbers must be kept in a secure location, and separately from the material to which it refers.
- 5.7 All completed forms, case notes and records, as well as any photographs, audiotapes and videotapes should be stored as soon as possible after use in a secure location, ideally in locked cabinets. Only one or two senior managers should have access to these secured storage facilities. As camp or field settings are rarely secure, additional measures may be needed to ensure the personal safety of those staff with access to the data storage areas (i.e. the key holders). Suitable arrangements must also be made if, at any time, materials have to be moved to other locations. As mentioned in the preceding paragraph, indexes for matching code numbers with identifying information/names should always be stored separately and securely.
- 5.8 Audio and video recordings of interviews should be destroyed once a transcript of the interview has been created. If audiotape or videotape is made for purposes other than simply recording an interview, the person responsible must not only justify why it needs to be made but also make provision for preserving the confidentiality of those featured in the recording, especially if it is to be kept for any length of time.
- 5.9 Participants in an information collection activity should never be recognizable through photographs, and/or audio or video recordings. Only images or recordings that have been blurred or changed (so that individuals are totally unrecognizable) may be used in reports, presentations or informational materials, or displayed on the Internet. If case histories are used to illustrate general findings, the content should be edited to remove any identifying details and thus avoid any possible identification of individual participants.

## BOX 6

### Mandatory reporting of sexual exploitation or abuse

The United Nations Secretary-General's *Bulletin on Special Measures for Protection from Sexual Exploitation and Sexual Abuse* establishes minimum standards for staff conduct in matters relating to sexual abuse and sexual exploitation (8). The Bulletin applies to all staff of the United Nations, including its separately administered organs and programmes, as well as to staff of organizations (or individuals) entering into cooperative agreements with the United Nations. Violations can result in disciplinary action, including summary dismissal, repatriation and/or criminal prosecution, as appropriate.

The Bulletin contains six specific standards for staff conduct, one of which stipulates that:

*Where a ...staff member develops concerns or suspicions regarding sexual exploitation or sexual abuse by a fellow worker, whether in the same agency or not ...he or she must report such concerns via established reporting mechanisms (8).*

Many nongovernmental organizations have adopted standards of staff conduct that are in line with the Secretary-General's Bulletin. So too have many donors, thereby obligating recipients of funding to adhere to these standards.

- 5.10 Those responsible for collection of information must have a clear plan regarding the permitted level of access to potentially sensitive information. The relative merits of identifying data sources (e.g. the region, ethnic group, village or camp) when sharing or publicizing information must be carefully weighed, bearing in mind the risk of potentially serious consequences to those who supplied data, even when individual identities are not disclosed. It is generally recommended that any public disclosure of findings, either in public presentations or publicly-available written reports or articles, should provide only aggregated, de-identified information (see BOX 4).
- 5.11 There are particular confidentiality issues that arise in the context of service provision. Caution must be exercised when sharing service data with others. It is advisable to stipulate conditions for sharing data and to put into place procedures for ensuring that the confidentiality of shared data is maintained (3). When exchanging information about individual case reports, all personal identifiers (name, location, exact date of the incident) should be removed. In order to provide services to survivors of sexual violence, it may be necessary to complete various medical forms and case notes. The confidentiality and security of these records must be maintained. A medical certificate, for example, should be given only to the survivor, or kept in a secure location until such a time as it is safe for the survivor to take possession of it and/or it is requested by the survivor. Note that the procedures for handling of medical records/certificates may be prescribed by national laws and policies. In this case, the information gathering exercise should comply with the laws and must consider, when planning, how such reports and documentation will be managed.
- 5.12 There may be mandatory reporting laws and/or policies in the setting that require certain individuals or professionals to report certain types of sexual violence cases. An example is given in BOX 6. Reporting requirements of this nature can create a dilemma for collectors of information about sexual violence because of the potential for conflict with key ethical principles, namely, respect for confidentiality, respect for autonomy and the need to protect the vulnerable. Given the very real risks that can arise, it is the responsibility of anyone planning to engage in collection of information about sexual violence in emergencies to:
- Obtain information about, and understand, any mandatory reporting requirements, including reporting mechanisms and investigation procedures **before** undertaking any collection of information. In some cases, such requirements and the prevailing local situation may lead to a decision not to undertake the information collection, or not to ask certain types of questions, because of the potential risks to participants and/or researchers.

- Formulate a strategy for addressing any issues relating to mandatory reporting that could conceivably arise.
- Inform potential participants about the information collector's duty to report certain incidents in accordance with laws or policies. This must be done as part of the informed consent process (see also Recommendation 6).
- Explain the reporting mechanism to the participant and what they can expect after the report is made.

In addition, researchers should ensure that these issues are discussed and procedures agreed with the relevant institutional, international and/or national ethics review bodies.

- 5.13 Mandatory reporting requirements in cases of child victims of sexual violence raise additional ethical and safety concerns. Children are more vulnerable and less able to act autonomously than adults. In the context of emergencies, there may be no effective services to help such children or reporting may start a chain of events that might put the child at even greater risk (such as being separated from his/her family or placed in an institution). In the absence of international consensus about how to handle mandatory reporting requirements in cases of sexual violence against children, investigators are advised to refer to the guiding principle of acting in “the best interests of the child.” The appropriate and required actions will differ depending on the conditions at the site where the information collection will take place (see also Recommendation 8).

# 6. Informed consent

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**Recommendation. Anyone providing information about sexual violence must give informed consent before participating in the data gathering activity.**

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The role of informed consent is to ensure that respondents are aware of, and *understand*, the purpose and content of the data collection exercise, the procedures that will be followed during the course of the exercise, the risks and the benefits to themselves of participating, and also their rights.

The informed consent *process* is crucial. It is much more than simply providing a form for participants to read and sign.

6.1 Careful attention must be paid to how information is given, considering issues of power and control in the setting. Those collecting information about sensitive subjects like sexual violence must recognize that – especially in emergency settings – individuals contributing information may feel beholden to them or dependent on them as a possible route to services. Thus, individuals may feel compelled to answer all questions, submit to examinations and/or agree to interview requests regardless of their own discomfort, risk or preference.

6.2 Information gatherers need to make sure they are not overly influencing participants with their authority, attitude, or demeanour, for example, their heartfelt conviction that the information collection is worthwhile, that it will not hurt the participants, and that professionals know best. Those collecting information should also be mindful of not making any unrealistic promises, in terms of benefits of participation, as this might unduly influence someone to agree to an interview.

Experience shows that respondents may misunderstand the purposes of interviews and/or misunderstand whether interviews will lead directly to an increase in or personal access to services. After working through the steps outlined in section 6.4 below, the interviewer should ask the participant to repeat back in her/his own words why she/he thinks the interview is being done, what she/he will gain by doing it, what she/he has agreed to, what the risks might be, and what would happen if she/he refuses. In other words, the interviewer must carefully assess each aspect of the participant's understanding and explain or rephrase the information as many times as required.

6.3 As part of the informed consent process, it is critical that participants are given information about each of the following (all of these should be communicated to the potential participant in what is often called a “consent statement”):

- the reason for the interview;
- the subject matter(s) to be discussed;
- the personal, and possibly upsetting, nature of questions that may be asked;

- the potential risk and benefits involved in participating (bearing in mind that respondents may misinterpret the possibility of personal benefit that may come to them if they agree to participate in an interview or other form of data collection);
  - the precautions being taken to protect confidentiality;
  - whether information will be shared, and if so, how and with whom (if identifiable information is going to be shared with third parties, the identity of these third parties must be disclosed);
  - their rights to refuse to take part in the interview and/or to answer any particular questions or parts of the interview and also their right to put restrictions on how the information they have given is used.
- 6.4 The generally accepted approach to obtaining informed consent is as follows:
- Read aloud to the interviewee the consent statement (see section 6.3 above), allowing time for questions and clarifications of individual points.
  - Having explained the key points, the interviewer should ask the participant to repeat back in their own words why they think the interview is being done, what they think they will gain from doing it, what they have agreed to, what the risks might be, and what would happen if they refuse. This will allow the interviewer to assess the participant's understanding of each issue, and if necessary, reinforce anything that was not clearly understood and correct any misunderstanding.
  - The last step, obtaining consent, can be done either verbally or in writing (see section 6.5).
- 6.5 Given the sensitive nature of the issue, asking for a signature to confirm that informed consent has been given may not always be appropriate. A signature will identify someone and possibly place that individual at risk. Two alternative strategies are:
- the interviewer can sign a form to confirm that consent was given by the respondent;
  - the respondent can sign a *separate* form which simply states that informed consent is given to participate in an interview (or other activity) but does not specify the topic.
- Thumbprint or X signatures may not be appropriate for respondents who are illiterate as they cannot read what they are "signing".
- 6.6 As previously mentioned (see section 6.3), respondents have a right to refuse to answer specific questions or to take part in sections of the interview. During the course of an interview, interviewers should therefore offer participants a number of opportunities to decide whether or not they wish to go on. For instance, a researcher could say, "The next few questions concern the most recent violent incident. May I continue?"

### **Good practice: obtaining consent for public disclosure of personal information**

Individual respondents or participants in a study or other such activity should never be asked to agree to have their identifiable information disclosed publicly, or their images used on videos.

Those wishing to create an informational video or to collect testimony that *will* be widely publicized, for example for the purposes of awareness-raising and advocacy, are advised to make a public announcement inviting volunteers to come forward to share their stories. Such announcements should be confined to appropriate communication channels (e.g. at women's centres), and must incorporate messages that are appropriate and acceptable for the setting and culture.

It is important to make sure that even those volunteering are fully informed of the possible risks and benefits of participating in this activity and given the option to stop their participation at any point.