

Confidentiality

Sharing data or trends on gender-based violence can help: ensure that services are responsive to needs, aid in targeting resources efficiently, and enable better coordination that will support quality care. Although the sharing of GBV data is important because it can help improve programs, push for needed advocacy or policy change and mobilize resources, there are also unique challenges. The survivors we serve have entrusted us, as service providers, with sensitive data that requires special protections and procedures. When this data is gathered, how it is stored and secured, and how and why it is shared with other actors, demands thoughtful and careful practices.

Data is not just a bunch of numbers. It's a representation of survivors, of their experiences, their stories.

In working in protection, these are often the traumatic, alarming or daunting experiences survivors share with service providers to receive care. This model of care is most effective when survivor receiving services can be open and honest and know what they share will be kept confidential. Indeed, this is one of the first questions beneficiaries and survivors often ask,

"Will the things I discuss be kept private?"

Confidentiality is the right of every survivor receiving services to have their identity kept private and unidentifiable. There is an implicit understanding and obligation on those providing services that any information disclosed by a survivor or beneficiary will not be shared with others, unless the person concerned gives explicit and informed consent to do so. This is part of the code of ethics we operate by. This is crucial to build and develop trust with clients, allowing for open disclosures. Trust between service providers and clients is essential to providing effective support, and typically depends on assurances of privacy. Disclosures are a function of confidence that the service provider will not share this information with others without consent.

For survivor to feel comfortable talking about intimate, private or revealing information or experiences, they need a safe space to talk without fear that this information will be revealed.

These standards for confidentiality and client privacy were formally endorsed in the Inter-Agency Standing Committee's *Guidelines for Gender-Based*



*Violence Interventions in Humanitarian Settings.*¹ Collecting and sharing GBV information can be dangerous to the survivors reporting, communities, and those involved in collecting the information.

“All actors agree to adhere to a set of guiding principles that minimise harm to the survivor/victim and maximise efficiency of prevention and response interventions. The guiding principles are incorporated into all elements of the plan of action for GBV prevention and response and should include, at a minimum: Ensure the physical safety of the survivor/victim and those who help her; Guarantee confidentiality; Respect the wishes, the rights, and the dignity of the survivor/victim, and be guided by the best interests of the child; [and] Ensure non-discrimination.”

“Provide security when survivors/victims report incidents to the police and/or security staff. Always respect the confidentiality, rights, choices, dignity, and confidentiality of the survivor/victim, ensuring that she is involved in any decisions or action to be taken regarding her security or protection. In the case of a child, be guided by the best interest of the child. All interviews with the survivor/victim must be conducted in private spaces and, preferably, by female staff.”

“Designate space for community centres, safe spaces for women/girls, child-friendly spaces, confidential access to sexual violence care at health centres, and other services and facilities related to prevention and response to sexual violence that allow for physical access, privacy, and confidentiality/anonymity.”

This information was further elaborated to set inter-agency standards related to the safety and ethical implications of doing GBV-related work and minimizing the risks of doing harm in the World Health Organization’s *Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies*.² The guidelines outline key ethical principles, including 1) Respect for persons: respecting the autonomy and self-determination of participants, and protecting those who lack autonomy, including by providing security from harm or abuse. 2) Beneficence: a duty to safeguard the welfare of people/communities involved, which includes minimizing risks and assuring that benefits outweigh risks. In addition, the WHO Guidelines highlight several key standards.

“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.

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

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.”

“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.

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.

Information gatherers need to make sure they are not overly influencing participants with their authority, attitude, or demeanor, 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 may 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.”

“Information gathering and documentation must be done in a manner that presents the least risk to respondents, is methodologically sound, and builds on current experience and good practice.”

One way to safely facilitate data sharing is to provide de-identified data. This is data that *“cannot be linked to a specific individual or group of individuals. To this end, all personal identifiers, such as person’s name, place of residence, and location and date of the incident, are removed from a data set or record. It may be necessary to consider removing other details to avoid possible identification of a specific individual or group of individuals. For example, if there were only a small number of women in a given age group in a given region, it might be possible to link data records which include age to individuals in this group. In this case, age should be removed from a data set or record.”*

Most recently the *Inter-Agency Gender-Based Violence Case Management Guidelines*, also highlighted our ethical responsibility.³

“Confidentiality refers to the right of a person to have any information about them treated with respect. It promotes safety, trust and empowerment. Confidentiality reflects the belief that people have the right to choose to whom they will, or will not, tell their story. Maintaining confidentiality means not disclosing any information at any time to any party without the informed consent of the person concerned. Breaching confidentiality can put the survivor and others at risk of further harm. If helpers do not respect confidentiality, other survivors will be discouraged from coming forward for help. In GBV case management, confidentiality is maintained through strict information sharing practices that rest on principles of sharing only what is absolutely necessary to those involved in the survivor’s care with the survivor’s permission. It is also necessary to protect written data about a survivor or a case through safe data collection and storage practices.”

“In most contexts, there are multiple agencies working together to provide different services to GBV survivors. This necessitates sharing information about cases and using referral forms with sensitive client data... actors involved in a referral network need to agree what information about survivors should be shared, when and with whom. How this information will be shared—verbally, electronically or through a paper system—also needs to be agreed upon and appropriate procedures put in place to ensure that the confidentiality of the survivor is protected at all times. This can be documented in an information sharing protocol.”

Even if pressured by a donor to share identifiable or potentially identifiable information about a survivor, our allegiance is to the international standards that govern our work and keep survivors safe. When requests are received, one helpful question to ask is, “Will this bring harm to the survivor?”

Then, consider why are we sharing this information? This can help you determine: what is the most effective way to share information, considering

the ultimate intended use: is it to show donors what has been accomplished? Is it to make a case for governmental partners so they can provide a service or improve access to a service that is in demand? Is it to show trends and patterns to potential partners and donors to mobilize resources? Data can help achieve those aims; however, practitioners have a great responsibility and accountability toward the survivors who have provided their information with consent, to treat it with sensitivity and act ethically.

Services are provided to survivors with their explicit consent to engage in the case management process, and personal information is shared, also with consent, for the purpose of making referrals to other service providers, or for anonymous, aggregate sharing for program improvement purposes. Considering the survivors that make up the data, the individuals that bravely sought services, it is our responsibility to ensure their rights to confidentiality are maintained and protected.



¹ Inter-Agency Standing Committee. *Guidelines for Gender-Based Violence Interventions in Humanitarian Settings*. 2005. <http://www.unhcr.org/453492294.pdf>

² World Health Organization. *Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies*. 2007. http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf

³ *Inter-Agency Gender-Based Violence Case Management Guidelines*. 2017. http://gbvresponders.org/wp-content/uploads/2017/04/Interagency-GBV-Case-Management-Guidelines_Final_2017_Low-Res.pdf