'Do no harm': Ethical evidence-building

One of the core principles of MHPSS programming is 'Do No Harm', and this applies to assessment and evaluation processes as much as it does to implementation.

The *IASC Common Monitoring and Evaluation Framework for MHPSS in Emergency Settings* highlights the importance of applying ethical principles to both research and M&E in order to avoid potentially risky or bad practices and keep all those involved safe. The Framework document draws specifically on the IASC *Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergencies*

The safety and wellbeing of participants *always* takes priority over conducting assessment and evaluation activities. At its simplest, ensuring this involves thinking through who could be harmed in the process of collecting information, and in what ways, then establishing practices to minimise this. We recommend that you refer to the resources already mentioned to get a better understanding of ethical practice in PMER-L, but we summarise key points here.

Safety of Data Collectors and Respondents

Participant and researcher safety are overriding priorities in emergency settings. Entering emergencies without sufficient safety planning is unethical and violates the principle of "do no harm". All research must include procedures for monitoring and responding to participant and researcher safety (IASC, 2014: 32).

Ensuring the safety of data collectors and respondents involves planning data collection with attention to conflict and potential risks, and careful training and supervision of data collectors (see section G). At the practical level, the procedures should enable both data collectors and respondents to conduct their work in settings in which they feel safe and comfortable. Data collectors should be trained to identify settings which are both safe and culturally appropriate.

Safety (and the 'do no harm' principle) involve attending to both existing and potential conflicts which may impact on the M&E project. The safety of all involved will be strengthened by maintaining impartiality and independence, and by the consideration of possible tensions and power structures (IASC, 2012). In situations where conflict is ongoing, all involved in the data collection must be aware of the parties involved in the conflict and of their dynamics, and care must be taken to avoid inflaming social tensions/conflict or endangering community members or staff (IASC, 2007: 42).

Systems must be in place to ensure that the location of data collectors is known to supervisors and that communication is possible in case of any difficulties. It is often advisable for data collectors to work in pairs.

Sharing Information about the Project with Stakeholders

An important factor in ensuring the safety and wellbeing of data collectors and respondents is to ensure that all stakeholders (including community members) have an accurate understanding of the purpose and nature of the M&E project. Where misunderstandings occur, stakeholders can become angry and aggressive, resulting not only in problems for the data collectors, but potentially ongoing resentment or anger towards those who participated in the project even after it is over and the data collectors have left.

Therefore, it is crucial that accurate and clear information is given to the community as a whole (often through community leaders) about the purpose of the project, what is involved in the data collection and how the information will be used (see section D on informed consent). This must take place before the data collection begins, but is an ongoing process since misunderstandings can occur at any stage. It culminates with a process of sharing the findings with stakeholders at the end of the project.

Whilst M&E findings can be sensitive and are often restricted to an internal audience, they should be shared more widely unless there are good reasons not to, particularly with the communities who are involved in delivering or receiving services from the programme(s) being evaluated. Good ethical practice also includes sharing M&E findings with the wider MHPSS and humanitarian community, in order to inform and improve emergency response. Dissemination to the academic and practice community ensures lessons are shared and used[1]. It is important to protect anonymity and confidentiality when sharing findings with any type of audience (see section F on confidentiality).

Participation/ Inclusion of Marginalised Groups

'Ethical research practice includes community participation throughout' (IASC, 2014: 21).

Three of the core MHPSS principles ('human rights and equity', 'participation' and 'building on existing resources and capacities', IASC, 2007) support the inclusion of the affected communities in the design and implementation of M&E activities, interpretation of results, and translation of results into recommendations. In addition to the affected populations, relevant stakeholders may include governments, NGO's, community and religious organisations, local research and university capacities (IASC, 2012).

Planning for M&E activities should include an analysis of differences and inequalities in society related to gender, race, age, sexual orientation, physical or intellectual ability, religion or socioeconomic status (IFRC, 2017), and strategies put in place to ensure that all groups are represented. The analysis of data should continue this process; disaggregating by sex, age and any other social distinctions that inform programme decision-making and implementation (IFRC, 2017). The M&E process should aim to correct, not reinforce, patterns of exclusion (IASC, 2007: 42).

Additional efforts are often necessary to ensure that individuals and groups who may self-exclude, be hidden or hard to access are included in the process, and that the findings reflect their experiences. Collaboration with formal and informal community networks and groups can assist in identifying and engaging these groups (IASC, 2014: 33). IFRC (2017) include guidance on how to ensure that children and young people are included in the M&E process in a safe and effective way, and you can also refer to this website [https://childethics.com/].

Informed Consent

Organisations must make every effort to ensure that the participation of community members in the assessment/ evaluation is genuinely voluntary (IASC, 2007: 42)

Whilst participation is a core principle underpinning MHPSS approaches, including M&E activities, it also presents a significant burden for those taking part. It requires time and energy and may remind people of hardship and difficult experiences (WHO & UNHCR, 2012: 19). Therefore, it is crucial that such participation takes place freely, with those involved being fully informed of all that is involved, including the purpose of the project, how and what information will be collected, how the information will be used, and potential risks and benefits to participants.

The potential outcomes of the data collection must be described honestly, even if it is likely that the evaluation may lead to no specific benefits to the community. Care must be taken to avoid raising unrealistic expectations during assessments (e.g. interviewees should understand that assessors may not return if they do not receive funding) (IASC, 2007: 42).

People must be free to decline or end participation without any negative consequences. In a humanitarian setting it can be more difficult to ensure that participation is genuinely voluntary, since M&E activities are often conducted by agencies that provide assistance, and people may fear they will lose the chance of such assistance if they do not take part in the data collection. (See IASC, 2014: 30 for a description of factors which can affect making a voluntary decision to participate in research).

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[1] See IASC (2014) for guidance on effective dissemination to different audiences

Obtaining informed consent is an ongoing process of ensuring that relevant information is understood; this requires some flexibility depending on the context and the needs of the individual respondent. Informed consent processes in emergencies must be rigorous but flexible, and adapted to the context. Local informants can help to ensure that consent procedures are appropriate. For children, people experiencing severe mental disorder and those who are unable to consent for themselves researchers will require alternative mechanisms for obtaining consent (see IASC, 2014: 31 for more information about the informed consent process with children).

Informed consent may be taken either verbally or in writing, depending on the context. Ideally, respondents will receive a participant information sheet which includes all the relevant information, and should sign one copy of this (which is kept by the data collection team) and retain the other for future reference (WHO & KCL, 2011: 24). There are circumstances where this is not possible, and other practices include: verbal consent; witnessed consent (someone other than the researcher signs); or the participant signs a separate sheet to indicate consent, ensuring their name is not linked to the study (for sensitive or taboo topics) (IASC, 2014: 25).

Responding to Distress

> Whenever possible, support must be given to respondents in need to access available MHPSS services (IASC, 2007: 42).

During the data collection process, it is possible that respondents may show signs of distress and the data collectors should be trained to respond effectively if this occurs.

Preparation for handling signs of distress during data collection

As part of preventing distress, it is important to make clear during the consent process that respondents may decline to discuss particular topics at any point (see section D on informed consent). However, regardless of the steps taken to make the interviews as safe an experience as possible for respondents, it is possible that some may become distressed during interviews. The training of data collectors should include guidance on how to respond if this occurs, which can include:

- You are not trained to assist the person directly
- Provide compassionate listening and accompaniment to someone who is distressed. Give her/ him the option to have a break or discontinue the interview.
- If they do not wish to continue, thank them for their participation and ask whether they want to be put in touch with someone who they can talk to. If they do, make that referral before the respondent leaves, and tell the respondent what will happen next.

Establish referral pathways before data collection begins

Some respondents may need to be referred to services which can provide more ongoing support. Before the data collection begins, individuals and/ or organisations who are able to provide mental health and psychosocial support should be identified, and systems put in place for referrals to be made in an appropriate, safe way. In some cases, referrals to other types of services may also be required. Where services do not exist, or service capacity is in question, a decision must be made about whether it is ethically possible to proceed with the data collection in the way originally planned.

Once systems have been established, all those involved in the data collection must be trained in when and how to make referrals for further support when needed.

Confidentiality and Data Storage

Confidentiality can be defined as 'conditions under which the information revealed by an individual participant in a relationship of trust will not be disclosed to others without permission' (UNICEF, 2011: 33-34).

Protecting confidentiality begins with the decision about where to carry out the data collection, and ensuring that information given by a respondent cannot be overheard by others. It should take place somewhere where participants 'feel free to speak without being watched, interrupted by others, reminded of things they need to do, and so on' (WHO & UNHCR, 2012: 20). Often this will be a quiet, private room, but this may not always be possible or culturally appropriate (WHO & KCL, 2011: 25). One alternative is to conduct data collection in a private space within settings which people visit for various reasons, such as health care centres.

In some cases, particularly when the respondents are vulnerable, extra efforts must be made to ensure that their involvement in the data collection exercise does not become generally known. The *IASC Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergencies* suggests that those planning the data collection discuss with local informants whether it is possible to conduct interviews in private, and that M&E teams put in place strategies for data collectors to follow in case the privacy of an interview on a sensitive subject is compromised (IASC, 2014: 35).

A second factor in maintaining confidentiality is ensuring that information given by an individual cannot become known by people outside the research team. Data collectors' training and codes of conduct (see section G) should require them not to discuss respondents' answers or personal details with people outside of the data collection team, even once the exercise is finished. However, if a respondent is discovered to be at risk of harm (or of harming others), confidentiality must be breached in order to protect safety (IFRC, 2017). The limits to confidentiality should be included in the informed consent process.

In addition, steps must be taken to ensure that data is made anonymous and stored securely. For example, pre-assigned numbers can be used on data sheets instead of respondents' names, with information linking respondents' names with their numbers kept separately (see IASC, 2014: 37 for further information on how data can be made anonymous). Systems of storing data securely should be put in place (see IASC, 2014: 38). This includes paper copies, voice recordings, photographs and electronic data.

Staff Selection, Training & Support

The selection of data collectors with the appropriate qualities and skills, training of the team so they can conduct the data collection in a professional manner, and the provision of supervision and support to data collectors throughout the process are also key elements of an ethical approach to M&E.

The evaluation process can enhance well-being, as respondents have the opportunity to express their opinions and share their experiences, but this will only be the case if the data collectors have the skills to behave in a friendly, respectful and non-judgemental manner throughout the interaction (IFRC, 2017). The way in which researchers conduct themselves and interact with people in the course of the research can support or undermine people's dignity and well-being.

A code of conduct can provide helpful guidance to data collectors in terms of expectations regarding their behaviour, but this cannot be a substitute for training and ongoing discussions of challenging situations which may occur during data collection. Recommendations for topics to cover during training of data collectors are included in the *IASC Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergencies* (2014: 41). Where the project involves interviewing children or other groups with particular needs, staff with the appropriate skills and experience should be recruited, and the training should include issues relevant to these groups (IASC, 2014: 43).

Staff care should be integrated into M&E projects, as with any other projects. Interviewers may feel upset or distressed by an interview, or find the interview process difficult (WHO & KCL, 2011: 26), so systems should be in place to support and mentor them throughout the process.

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