

**TRAINING PACKAGE FOR USING SOCIAL SCIENCE IN COMMUNITY ENGAGEMENT AND/OR COMMUNICATIONS ACTIVITIES**

**SESSION 3.1:** Ethical principles and approvals for social science research in a humanitarian/emergency context

SESSION CONTENT

**Learning approach:** Real-time presentation, discussion, case examples

**Delivery mode:** Online and offline, 100 minutes approx.

**Summary:** The session covers the main ethical principles that should guide social science research – an important responsibility of the researcher which must be upheld. This session discusses formal ethical requirements and approval processes and what happens when formal approvals are either not possible or not clear. It also explains the importance of gaining community approval and how this might be achieved.

**Learning outcomes:**

* Know the key ethical principles that guide social science research
* Become familiar with the different ethical requirements and approval processes when doing operational social science research in a humanitarian context
* Understand the importance of gaining community-level approvals

FACILITATING THE SESSION



**TRAINING PACKAGE FOR USING SOCIAL SCIENCE IN COMMUNITY ENGAGEMENT AND/OR COMMUNICATIONS ACTIVITIES**

Introduction: (5 minutes total)

Talk through session summary and learning outcomes.

Position this session in the question flow, highlighting that ethical principles are an important consideration   
across the whole process.

1. How to ensure that this information goes back to communities? To inform community-level actions and decision-making of the broader response?
2. What methodology and tools should be used to collect and analyse this information?
3. How to track the information used to ensure that it effectively contributes to operational and strategic priorities?
4. Who can collect this information?
5. Does this information already exist? Is there a related needs assessment or study?
6. What information is needed?

**DATA TO ACTION:**

Key questions in social science research

1. Who needs this information?
2. How to ensure that the information is used to make operational and/or strategic decisions?

Key ethical principles (25 minutes total)

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|  | Question to participants (10 minutes):  Consider your current work with communities. Which ethical principles guide your work?  Online: Invite the participants to write the answers in the chat function and summarize  Offline: Take four or five answers from participants in the room |

Ethical practice should first and foremost reside with the person or people conducting the research.

The ethical principles that guide operational social science research include respect for persons, doing no harm, and justice. These are applied practically in different ways, including getting voluntary informed consent from participants, allowing the right to withdraw from the research at any time, maintaining privacy, weighing risks and benefits of participating in research, and in the selection of participants. Table 1 outlines how these connect together, and gives more details on each.

**Table 1:** Ethical principle and what it means in terms of application

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| Ethical principle | Application |
| **Respect for persons**   * Individuals should be treated as independent individuals, not under the control of others * People with diminished ability to act independently require special protection | **Informed consent**   * The person should have the capacity to give consent and should have the power of choice without constraint or coercion – without feeling forced or persuaded * The person should have sufficient knowledge and understanding to enable him or her to make the right decision * Participants must be fully informed about: * The research aims, risks and benefits * The procedure (what will happen, how long will it take) * Their right to refuse participation or to withdraw at any point * How participants were selected (e.g. why me?) * If someone is under the legal age of adulthood, ‘assent’ should be gained from them, and consent should be gained from a caregiver over the legal age of adulthood   **Right to withdraw**   * This should be possible at any time during the research, without consequence * This includes the right to ask for the tape-recorder to be switched off   **Privacy and Confidentiality**   * Respect confidentiality – participants should be able to choose whether their statements are public and attributable (quoted ‘on record’) or whether their statements are anonymous or not to be quoted (‘off record’) * Respect privacy – participants should be able to speak in a comfortable setting free from onlookers; participants should never be forced to reveal information about themselves that the participant does not wish to reveal. Note: notions of ‘privacy’ and propriety are highly specific; for example, in some environments people may discuss sex and sexuality very publicly, while in other settings these topics may be taboo. Seek local guidance on what is appropriate * Data should be anonymized (where the participant does not request attribution), identifiable information should be removed and data should not be able to be linked to any one person * Data should be stored securely |
| **Do No Harm**   * No harm should be done to participants * Beyond this, benefit should also be gained from participation in research. Common questions researchers ask themselves include: Should this be a social or a personal benefit? Who should decide what the benefit should be? * Research should be necessary and meaningful – the research should be unique and it should contribute to the greater good | **Assessment of risks and benefits**   * The nature of risks and benefits should be assessed in a step-by-step way. This should include speaking with communities who will participate in the research about what the potential risks and benefits could be * ‘Risk’ can be defined as: the probability of harm or injury (physical, psychological, social, or economic) occurring as a result of participation in research * The potential benefit of the work should outweigh the probability and severity of risks. Any possible risks should be minimized * More information on assessing risk can be found [here](https://www.research.uci.edu/compliance/human-research-protections/irb-members/assessing-risks-and-benefits.html). |
| **Justice**   * Treat people equally, fairly and respect  their rights * The risks of research should be negligible | **Selection of participants**   * When selecting participants, wherever you can include  a wide range of people; think about gender, ethnicity,  and marginalized groups |

See the [Belmont report](https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html) for more information on ethical principles.

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|  | Question to participants (10 minutes):  How might humanitarian settings present additional challenges to applying these ethical principles?  Online: Invite the participants to write the answers in the chat function and summarize  Offline: Ask two or three participants to share their thoughts |

**Differences in power** that may potentially exist between researcher and research participant may be much more amplified, especially in a scenario where the researcher is coming from outside the emergency context – e.g., the researcher may see themselves as a sort of ‘rescuer’; participants may believe their cooperation is essential to receiving assistance.

People might find themselves in the most vulnerable moment of their lives. The idea of informed consent may not be able to be applied in practice as intended. Specifically, ‘the power of choice without constraint or coercion’ may be complicated if people are not used to exercising choice, or if they are in a desperate situation and **hope something may come from their involvement** in the research (e.g. food, shelter, protection).

It should be made absolutely clear that the research is independent of other forms of assistance and that it is not necessary or obligatory for people to participate.

**Privacy** may also be harder to ensure in the reality of a humanitarian emergency. For example, in a crowded refugee camp setting people may be coming and going from a meeting place, children may be peeking under the flaps of the tent to see what's going on.

It may also be more difficult to **store data securely** during an acute emergency where there are no fixed office spaces and/or internet connectivity is poor.

These principles first and foremost are the responsibility of the person conducting the research to uphold.

We will talk in more detail about these challenges, and will hear more about your experiences, in session 3.2.

Ethical requirements and approval processes in a humanitarian setting (35 minutes total)

It is important for facilitators to be familiar with the specific context trainees are coming from so they understand the type of approval processes that might be considered

Formal ethical approval from an institutional ethics review board (ERB) is often required for formal research to be carried out. Sometime ethical approvals may be needed/granted by individual response agencies who have their own internal ethical processes.

It is important to understand the national rules and regulations of the context you are working in (in addition to the rules and regulations of the response agency you may be working for). Here we review some of the most common environments that need to be considered when seeking ethical review and approval for a piece of research:

* **University review boards** – These are most common and are usually fairly well established and ‘well oiled’, with the most predictable timeline. Often there will be a special department or stream for social science research.
* **Institutional/agency review boards** – These do not exist in all institutions. Humanitarian institutions are rarely primary research institutions, and so they review less frequently than universities. The types of research they review can also be quite diverse, which means they need to be flexible and multi-skilled.
* **National/governmental review boards** – Again, these may not exist, and where they do they tend to have diverse requirements.
* **Community approval** – While it is rare for formal ethics boards to exist at the community level, other governance or welfare structures may exist – for example, an elders’ committee or a patient support network. In the context of this training package, this might be the most important level to consider.

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|  | Question to participants (10 minutes):  Why do you think ERBs exist?  Online: Invite the participants to write the answers in the chat function and summarize  Offline: Ask two or three participants to share their experiences |

**Why do ERBs exist?**

These mechanisms exist to protect the participant and the researcher. They are there to make sure key ethical principles are considered in the design and in the roll-out of research.

However, criticisms of ERBs are common. One criticism of ERBs is that they can come to play a risk management role (rather than a community protection role) for the organization or the institution itself. This can manifest in complicated procedures for research approvals which may be disconnected from the reality of working in a humanitarian/emergency context.

It varies across different institutions, but the application process for an ERB approval can be administrative and time-consuming. In a humanitarian setting – where you do not have much time and need to act quickly – this can be particularly problematic.

The number of levels you may need to apply for can also make the process costly, which can be a barrier for less well-resourced research initiatives.

Some of the most powerful benefits of qualitative research projects in emergencies are that they can be light, cheap, portable and can be deployed quickly. However, lengthy, complicated and costly ethical approval processes can undermine these benefits.

The humanitarian community has yet to tailor the ethics review process to the setting and to the method – it is largely still a one-size-fits-all approach in our ethics review processes. In order to promote the use of qualitative and mixed method research, review boards need to have social scientists that are part of the review process to properly evaluate (and give proper consideration to) proposals which focus on qualitative methods and other methods more widely used in risk communications and community engagement.

**When is research, research?**

Whereas formal ethical approval is required for ‘research’, it is often not required for activities including ‘assessment’, ‘monitoring’ and ‘evaluation’, ‘quality improvement’ or ‘service evaluation’ which may, on paper, be the same. The distinction between formal ‘research’ and these other activities is not always clear cut. This can lead researchers to question what they should call their work, in order to pass through (or avoid passing through) formal ERB processes.

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|  | Question to participants (5 minutes):  Are ERBs best placed to make sure the principles of ethical research are followed?  Online: Invite the participants to write the answers in the chat function and summarize  Offline: Ask two or three participants to share their experiences  Note for facilitator: this is a question that attracts a lot of controversy and participants may have strong feelings either way. Answers will be very dependent on the group of participants, the type of work they do, their past experiences, and the country context. It is your role to draw out the different perspectives, but not to conclude what the ‘correct’ answer is. Above all, the core ethical principles of respect, do not harm and justice should be emphasized. |

This is an issue that attracts a lot of debate. There are strong arguments either way. In addition to what we have already discussed, there are downsides to not getting formal ethical approval for your activities – you usually cannot publish findings and so you cannot contribute to the scientific body of knowledge in the same way. There is a risk of blurring people’s perspectives of what is research versus what is advocacy versus other forms of engagement with communities. This lack of clarity and blurring of lines can lead to confusion and mistrust.

The key takeaway is that, as important as national or institutional ethical approval can be, this should not be the key to ‘ethical research’. The main thing is that researchers carry the ethical principles with them throughout their work, and use them to guide their decisions and actions. Ethical practice should first and foremost reside with the researcher, despite whatever formal approvals they may or may not be required to go through – respect, do no harm, and justice should be the guiding principles of any ethically guided activity in a humanitarian/emergency context.

If we do submit for institutional ethical approval, how can we best do it smoothly?

* It is highly advisable to get assistance from someone who has technical experience and also expertise in going through these types of processes.
* There are fast-track options in many ERBs for when there is a perceived urgency to the research or a perceived lower risk involved in the research (meaning the approval process can be sped up). These rapid approvals depend on the institutions, but generally qualitative research is a good candidate for more rapid research approvals.

**What happens when an emergency has resulted in review structures being dismantled?**

There are scenarios wherein the usual structures for ethical review and approval are completely dismantled by the crisis. We now present one situation on how this was navigated by researchers.

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|  | Case example (10 minutes):  In the years following the outbreak of civil war in an African nation, existing academic, government research and civil society institutions struggled to continue, as funding sources dried up – e.g. the government cut funding for science and higher education in favour of military spending, while development money that could have funded this area instead fled the country. Universities are generally given a lower priority in situations of humanitarian emergency, and donors don’t often consider funding the higher education sector which as we just learned, if often the most common and well-established location for university ethical review boards. Members of the African nation’s already small social science community found themselves in difficult personal and financial circumstances – e.g. they carried on their teaching and research duties without pay. At the same time, the conflict led to an influx of external research interest in the country. The significant number of foreign academics and humanitarian agencies who wanted to conduct research contacted the remaining members of the national social science community with requests for collaboration and review. Since the spirit of academic collaboration is to give freely of time and knowledge, and there is often an assumption that research is unquestionably a public good, the expectation was often that this collaboration would be free of charge. The researchers quickly became overwhelmed with (uncompensated) requests for their time. |



Reflection question: What could have been done differently?   
Has anything similar happened in your settings?

**Key message:** Linking back to what we have just discussed, researchers should carry ethical principles with them throughout their work, and use them to guide their decisions and actions. Ethical practice should lie first with the researcher and not the system; as we have seen above (and maybe some of you have experienced directly) the system can fail.

Approval from communities (30 minutes total)

So far, we have discussed institutional validation of research.

But perhaps the most important review and approval process for truly ‘ethical research’ should happen at the level of the community affected by the issue in question. Can we really know whether this research will ‘do harm’ if we don’t ask the people who will be directly involved/affected?

Whereas institutional approval is a moment in time, community approval and acceptance is ongoing and may need to be re-negotiated and re-established every day.

This component of the research is probably the most critical, and also potentially the most meaningful, for grounding ethics in lived reality. Careful reflection of what ‘community approval and acceptance’ of research is or could be, can often reveal unexpected or overlooked benefits or risks and offer a more realistic appraisal of research potential.

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|  | Brainstorm (10 minutes):  How might ethical approval be approached with communities involved in the research?  Offline: Small working groups or discussion in pairs  Online: Write in chat or map using digital tools  Reconvene in plenary, note down answers on flipchart paper |

How can we go about gaining approval from communities?

* Acknowledge the leadership of the community
* Acknowledge the members of the community
* Ask their permission to enter the community
* Explain the research that you are planning to carry out and the potential benefits and risks. Ask how they view the risks and benefits. Are they relevant? Are there any others to consider?
* Seek permission to conduct the research
* Consider who you obtain permission from. Is it enough to achieve it from elders? Or should you be seeking it through other groups? Consider who you ask and who they speak for
* Be prepared to continue doing this every day, if need be, during the research process
* Consider establishing formal mechanisms such as community advisory boards that can oversee ethical issues during the roll-out of research (particularly important for longer-term, protracted crisis situations)

See **Handout 1** for an example of an information note used to discuss a piece of research with community groups. As this form of communication did not suit everyone and/or not everyone consulted was literate (refer back to language principles presented in session 2.4), the information presented in this information note was also used as a basis to develop a variety of PowerPoint presentations and oral presentations with visual aids, all tailored to different audiences and all with the intent of explaining the work and gaining individual or group consent.

The role of communities in the management of research is growing. For example, a best practice in **indigenous health research** (IHR) in Australia and North America, involves placing primary responsibility for research governance with the communities where the research will take place. In practice, this might mean the community convenes its own research jury, consisting of community members, to assess the risk and benefits of the research. Or it may go so far as the affected communities being given complete control over the research budget, and the hiring and management of investigators, to explore a research question that the community themselves define and prioritize.

To read a summary of IHR, please visit their website [here](https://iaphs.org/best-practices-research-indigenous-communities/). To learn more from Memorial U, a world leader in this approach, visit their website [here](https://www.mun.ca/research/Indigenous/faq.php).

A paper that reviews a ‘health research jury’ can be found [here](https://pubmed.ncbi.nlm.nih.gov/26260982/).

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|  | Individual exercise (15 minutes)  Read ‘Social Science Research in a Humanitarian Emergency Context’ chapter (**Handout 2**).  This case highlights the issues raised above about research needing to be independent of other forms of assistance. It also raises the importance of paying attention to local social norms and communicating with local communities.  What are the other key lessons learnt takeaways from the case study? |

Wrap-up/summary (5 minutes)

* The ethical principles that guide operational social science research include respect for persons, doing no harm and justice. These are applied practically in different ways, including getting voluntary informed consent from participants, allowing the right to withdraw from the research at any time, maintaining privacy, weighing risks and benefits of participating in research, and in the selection of participants.
* Ethical approval from an insititutional ethics review board is often required for formal research to be carried out. It is important to understand the national rules and regulations of the context you are working in. The humanitarian community has yet to tailor the ethics review process to the setting and to the method – it is largely still a one-size-fits-all approach.
* Despite the existence of these institutional approval processes, researchers should carry ethical principles with them throughout their work, and use them to guide their decisions and actions. Ethical practice should lie first and foremost with the researcher and not the system.
* Perhaps the most important review and approval process for truly ‘ethical research’ should happen at the level of the community affected by the issue in question.

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