

## 3.4

# Ethics in Research

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### 3.4.1 Learning objectives

To understand the following key concepts in research ethics as they apply to health emergency and disaster risk management (Health EDRM):

1. The role and importance of ethical considerations throughout the different phases of a research process.
2. The limitations of normative ethical guidelines when operationalized in emergency and disaster contexts.
3. The importance of reciprocal community engagement in ensuring valid and valuable results.
4. The role of project managers, research funders, national governments and research ethics committees.

### 3.4.2 Introduction

Emergencies and disasters significantly impact people's health and livelihoods. Whereas the health sector has traditionally focused on emergency response, Health EDRM shifts risk management to a more all-encompassing, proactive approach that emphasizes prevention and mitigation, alongside preparedness, response and recovery, across multiple hazards and reducing vulnerability through building community capacity (1).

Decisions and priorities in Health EDRM in both programmes and research must involve ethical considerations that minimize short and long-term harm in a transparent manner (2). Ethical guidelines are not simply obligatory approval mechanisms but are tools to promote more equal researcher-participant partnerships and uphold integrity throughout a project's life-course, from research design, review, implementation to publication (3-4), in a way that protects and respects the community's welfare (5). Ethical guidelines take into consideration the value of undertaking the project itself, assessing its contribution to social good,

3.4

potential to save lives and reduce suffering, and the significance of knowledge outcomes. The consequences of failing to ensure ethical considerations are addressed can lead to problems of moral significance, such as loss of public trust, disruption of livelihoods, confusion about roles and responsibilities, and low morale of both researchers and participants (6).

### 3.4.3 Limitations of normative ethical guidance

There is an ethical imperative to collect good data in all research. In Health EDRM, such data are essential to provide public health and clinical practitioners with high quality evidence on which to assess the impact of a crisis, identify necessary risk management measures and plan for future interventions (7). Appropriate research findings are often lacking in the field of Health EDRM as many interventions are not evaluated in rigorous trials that result in evidence of adequate depth and quality (3, 8).

Emergencies create unique challenges in logistics, security, resources and time-management (9). Standard processes and procedures designed to operate in non-emergency circumstances may not be sufficiently flexible to adapt to the uncertainty inherent to disasters. However, changes to process or methodology can be perceived as undermining ethical rigour (8, 10). Lower income countries are disproportionately impacted by disasters since technical capacity, governance and resources may be both limited and poorly coordinated, putting further strain on research implementation (6). Other areas where there may be particular pressures during disasters that are not well addressed in normative guidance include: determining a fair approach to research participation; duties and roles at the interface between research, treatment and public health; management of expectations on the front line; and protection of participants from stigmatization, discrimination and exclusion (10).

Despite these challenges, there is consensus that stakeholders must prioritize the interests of communities involved (see also Chapter 2.7), many of whom are at their most vulnerable during and after emergencies and disasters (5). Pressures in time and situation should be assessed in the overall context and should not be excuses for bypassing the underpinning ethical values that ensure research is rigorous and fit for purpose (7). Case Study 3.4.1, and the rest of this chapter, identify ways in which these values can be upheld despite the challenges to the procedures through which they are operationalized in non-disaster situations. These include the creation of specialist scrutiny committees and a strong focus on partnership working – to the extent possible – with affected communities.

**Case Study 3.4.1****Deviation from normative procedure: use of unregistered interventions for Ebola in West Africa (11)**

During the 2014 West Africa Ebola outbreak, the rapidly rising case fatality rate under a fragile health system prompted calls to accelerate the development of interventions that were successful in laboratory and animal models, but had not yet been evaluated for safety and efficacy in humans. A WHO expert panel considered the ethical implications of using promising unregistered interventions outside the context of standard clinical trials (11). The panel concluded that although this was a departure from well-established systems of regulation, it was acceptable on ethical and evidential grounds to offer the experimental interventions in the absence of any existing effective interventions, and under these unprecedented, exceptional circumstances (12). Relevant ethical considerations both in the initial decision and in subsequent requirements for implementation included:

- The need to prioritize essential public health measures and resources
- Transparency to participants about the status of medical products and their uncertainty
- Transparency on risks and benefits
- Informed consent and freedom of choice, emphasizing the preservation of dignity
- Fair distribution of products in the event of scarcity
- Community involvement
- Full capacity by the research team to monitor and manage any side-effects and progress of treatment.

The panel also stressed the moral obligation of researchers to rapidly and transparently share all relevant data with the scientific community. Researchers have a moral duty to continue the evaluation of these interventions in clinical trials (see Chapter 4.1), in order to establish the safety and efficacy of the interventions for both current and future benefit (11).

**3.4.4 Value, feasibility and validity**

The need to justify research in communities during or after emergencies is intensified in the light of the constraints described above. Decisions about research must take into consideration value, feasibility and validity:

**Value:** Identifying the necessity and added value of the proposed research is essential in justifying access to the available financial, human and time resources. It is therefore crucial for the research design to consider unmet needs of the target community (3).

**Feasibility:** Feasibility and purpose, not just desirability, should steer research design. This includes: considering whether research should be done immediately after a disaster, or at a later point; the method and duration of data collection; or whether the research question needs to be adapted (3, 13, 14). Importantly, research should be conducted in ways that are compatible with the existing healthcare response and public health needs (15).

## 3.4

**Validity:** Unreliable or unusable findings can interfere with good practice and take up necessary resources during times of need. Reviewers have sometimes found that Health EDRM research lacks reliability and validity, which undermines its contribution to establishing baselines, standards, or trends (7, 16).

It is critical to explicitly acknowledge any limitation. Researchers should also consider the risk of not undertaking research, or of prioritizing one project over another. Ultimately, researchers must consider the benefit of a project along with the cost of a missed opportunity.

### 3.4.5 Participant selection and exclusion

Research participation must be determined fairly, equitably and in line with objectives – and not due to privilege, access, perceived vulnerability or other subjective factors. Any exclusions should be based on valid scientific justification (3). Those who are at particular risk of exclusion include those marginalized due to their age, gender, ethnicity, pregnancy, or previous trauma. Furthermore, damage to geographical, physical or governmental structures during emergencies could become barriers to access that result in research participation being decided on grounds of convenience rather than scientific validity (7). Failure to include the necessary groups creates a knowledge gap in understanding the impact of an event across the entire population (17). Exclusion can be particularly harmful in behavioural or mental health research (see also Chapter 5.1), as there is evidence that these marginalized groups experience significant long-term emotional and physical consequences following disaster events.

### 3.4.6 Informed consent

Informed consent is a process whereby potential research participants decide whether they wish to participate in a proposed study, having clearly understood the purpose and process of the research, including its risks and other implications. An informed consultative process has the potential to empower participants, build capacity, resilience and agency, and facilitate early identification of rights violations (18). It is the researcher's duty to ensure that all necessary information has been communicated transparently, with consideration given to participants' health literacy, language barriers, and that decisions made by participants are well-informed, autonomous and voluntary.

While mainstream international guidelines unanimously agree that participant consent is mandatory, obtaining the appropriate informed consent can be practically challenging in Health EDRM. An individual's desire to survive may alter their perception of the potential harms of research participation. Researchers are often perceived as having the power to effect change, and it is crucial to be aware of power differentials and to not take advantage of potential participants' desperation and mistake this for voluntary and informed consent (19-20). Populations in situations that render them particularly vulnerable, and who may lack clinical or research knowledge, are more likely to participate in research under the expectation of receiving assistance or monetary compensation without fully understanding underlying risks (18). Although it cannot be assumed that all survivors of emergencies have impaired decision-making capacities, researchers should incorporate safeguards to ensure adapted

procedures are used for particularly vulnerable groups in order to not exclude or exploit them based on any perceived vulnerability (7, 21).

Innovative ways have been developed to improve informed consent. For example, members of the community can be involved within the research infrastructure so as to contribute local perspective, act as translators to inform potential participants, and become trained in research methods themselves (3).

### **3.4.7 Harm-benefit**

Health EDRM researchers operate in unstable contexts and so unforeseen obstacles will occur – the extent of which can range from inconvenience to participants, to psychological discomfort, loss of dignity or inflicting physical harm (13, 21). In justifying the added value of research, any potential harm must also be considered, taking into account the novelty and necessity of the research (20).

In practical terms, there is an ethical responsibility to structure research in a way that minimizes risk exposure by balancing risk with protective measures to alleviate burden and distress, particularly for participants who may be made more vulnerable by their age, gender, ethnicity, disability or previous trauma. Community representatives could be recruited as advisers in the planning process, to ensure researchers have an understanding of potentially controversial topics, such as those involving gender roles, family dynamics, political beliefs, and abuse. International researchers in particular must be cognisant of how their presence and behaviour may be perceived by the community (3, 20).

In addition, researchers must consider risks to themselves and ensure they do not cause additional burden in settings facing geographic, political or medical instability (22). Potential harm can be mitigated through training in cultural awareness, psychological support, security and practical protection measures. Research supervisors and funders are responsible for delaying projects until risks decrease, should this be necessary, and for not placing front-line researchers into high-risk settings without appropriate protection (3, 20).

### **3.4.8 Participant protection**

Research can be intrusive, so it is necessary to protect participants' interests while maintaining methodological rigour, particularly where vulnerability is exacerbated. To the extent possible, participants should be viewed as 'collaborators' and never just as 'data' (23). At the same time, researchers must be alert to the potential power differentials, and associated risks of misunderstanding and exploitation. Welfare, privacy, confidentiality, protection from stigmatization and respect to gender, religion and culture must be acknowledged, regardless of urgency (3). In order to be able to recognize what might constitute "harm" or "stigmatization" within a population, community involvement during the study development phase is crucial, especially where international researchers are involved. A breach in trust, or reinforcing stigmatizing factors, can result in harm to participants or wider communities, and in compromising the research, can in turn impact public health outcomes (7).



## 3.4

To protect both participants and their information, researchers should include the following operating procedures (7, 24):

- Avoid exposing participants to further harm as a result of the research, including physical and psychological harm.
- Respect each participant's freedom to withdraw from research.
- Assist participants in understanding their rights and any potential risks in a manner they can understand. Consider involving local representatives in sharing necessary information between the participant and research groups, as community awareness can reduce anxiety and promote ownership.
- Do not collect information that is not related to the research activity and minimize the use of identifiable information, such as by using codes to refer to participants rather than names and addresses. Irrelevant data collection wastes resources, and adds a burden to data storage and protection (see also Chapter 4.4).
- Be explicit about the intended use of the information collected, and the circumstances under which it will be collected and shared.
- Securely store information and ensure access is limited. Physical data should be locked, and electronic data should be password protected and encrypted. Assign "record-keepers" within the research team to oversee data storage and sharing, which includes distribution method and to whom it is shared. Technological advances continue to shift the benchmark for what constitutes as secure, and it is important for those responsible for data management to keep up with such advancements.
- Fully consider the impact of publishing findings, including the consequences of not doing so, such as the reaction of national governments or other relevant authorities.

Case Study 3.4.2 provides an example of the importance of research participant engagement in conducting research relevant to Health EDRM.

**Case Study 3.4.2****Research participant engagement during the 2006 Israeli-Hezbollah war in the Lebanese Republic**

Research undertaken by the American University of Beirut sought to assess the psychosocial status and needs of the internally displaced people in order to inform appropriate psychosocial interventions in wars. In addition to methodological difficulties, such as security and access, the experience of the researchers illustrated how conducting surveys in wartime intensifies certain ethical considerations. Important considerations arising out the researchers' experience include:

- Different expected outcomes between researchers and participants. Some participants attempted to expand the research focus into issues that addressed other needs, which caused diversions during data collection, sometimes resulting in overt conflict that was not easily resolved. Researchers have an ethical duty to clarify expectations, even if this decreases the likelihood of participation. This experience further emphasizes the importance of prior community engagement in order to identify priority research needs.
- The scope for harm in asking participants to reflect on a traumatic experience. It is important to be sensitive to individuals' reactions in these discussions. While some may feel indifferent or feel relieved and unburdened, others may be negatively triggered. In this case, data collectors were asked to stop the survey at first sign of distress and shift to casual conversation.
- Approaching potential participants who may feel humiliated by their living conditions. Media images from the camps showed some of those living there covering their faces. Survey participants were given the opportunity to describe their pre-war living conditions, which many did with pride.
- Concern that communities felt obliged to participate in return for assistance or provision as it was political "gatekeepers" and welfare providers who were linking students with participants. It is the responsibility of the researcher to ensure participants have freedom of participation, with no sanction resulting from refusal (25).

**3.4.9 Community engagement**

Ethical integrity in research is rooted in mutually respectful partnerships between researcher and participants, which increases the likelihood of developing mutual trust, of local ownership of the research aims, and of generating results that are valuable to the community. Researchers should work to achieve relationships that are as reciprocal, collaborative and transparent as possible, where participants feel their needs and interests are acknowledged (6). Time pressure during emergencies should not be an excuse for researchers failing to engage (15).

Effective and respectful community engagement starts with recognition of the broader situation, experience and practice of the affected population, as these are factors essential to people's identity, dignity and reactions. This can include understanding: the successes and weaknesses of the local health system; the situation of staffing, structure and resources;

## 3.4

unmet needs; familial and community relationships; and culturally or politically sensitive subjects. Historically, emergencies have most impacted those with limited financial resources, education and knowledge about clinical research, so special measures should be taken to include representatives from all subgroups, including the most marginalized to the extent that is possible, in order for the research outcomes to reflect their needs and experience, and to generate useful, valid data (15, 26).

For the research to be appropriate, for the community to understand the objectives, and for relevant harms and benefits to be identified, participants' communities must be consulted continuously in a two-way process throughout the design, implementation and reporting of research (10, 14). This can be achieved through identifying key stakeholders, including political, military and religious leaders, local media, social influencers and women's organizations at the earliest opportunity. Information can be gathered through focus groups, surveys or interviews with diverse community representatives, and in turn shared by integrating and coordinating within existing services such as community health workers (15).

Some have suggested that by participating in relief efforts or volunteering within the community, researchers can build a rapport, and promote mutual understanding about the research goals (27). However, this relationship can cause confusion in distinguishing researchers from responders, and blur the line between research and provision of care. Regardless of potential benefit to participants, the purpose of research is to achieve scientific goals and contribute to knowledge, and the potential for therapeutic misconception must be acknowledged. This can include misinterpreting the benefits of an intervention or, conversely, downplaying harm. Some ethicists have even suggested that informed consent should include clarification on the differences between research and provision of care (28).

It is important to not promise what cannot be delivered and to maintain a respectful relationship between researcher and participant. Furthermore, effective communication and feed-back mechanisms are essential for addressing rumours or misunderstandings, which are grounded in valid experiences and should not simply be dismissed. Communities must be able to receive information about research progress and outcomes in ways that are respectful of their contribution (15).

### 3.4.10 Stakeholder roles and responsibilities

There are other important stakeholders in the research process, beyond the researchers themselves, who have responsibilities in ensuring a project is planned, designed, and implemented appropriately. These include research managers, research funders, national governments and research ethics committees, as outlined below. Other stakeholders also include civil society organizations, other local research facilitators, and members of the international community.

### **Research managers**

Research managers should encourage needs-based collaboration, national ownership and sustainability of a project, which includes avoiding the “parachute” or “lone” researcher model. Managers are accountable for the safety and welfare of their front-line staff, and need to take appropriate action to manage both the inherent risks staff face in working in dangerous settings, and any additional risks associated with the research. Staff must also be provided with adequate guidance in identifying and managing practical ethical issues throughout the life-course of the project. This includes completing cultural sensitivity and security training in order to successfully work in complex settings, and ensuring access to ongoing support as needed. Local partners and staff can help international organizations interpret and respond to certain situations; however, these local staff must also be protected from unfair employment practices or mistreatment from their community as a result of being involved in research (15, 29).

### **Research funders**

Research funders should be fully informed on resource and access constraints during emergencies and disasters before defining or prioritizing activities, in order to avoid unrealistic and subsequently unmet expectations. They should actively promote collaboration and encourage capacity development and community engagement in research projects. This can include providing resources to enable partnership with local entities or civil society organizations. Having a holistic view on projects, research funders should monitor potentially duplicative research in order to avoid unnecessary research burden on participants (10, 13, 17).

### **National governments**

National governments are responsible for strengthening their emergency preparedness under the International Health Regulations (2005). This includes overseeing and pushing forward the scientific agenda for coordinated, integrated, partnership-based research, in particular by supporting academic and research capacity strengthening for the development of national expertise. National governments also have a role in overseeing and coordinating research to ensure competing research priorities do not overburden the population. This is particularly important during emergencies, where the influx of multiple agencies may cause confusion over roles and mandates (15).

### **Research ethics committees**

Research ethics committees (see Chapter 6.4) are responsible for promoting high ethical standards, which include overseeing participant protection and accounting for potential risks (30). Although there is agreement that the research ethics governance systems need to be timely and flexible in the context of Health EDRM, and that committees should have relevant technical capacity to assess these projects, there is little consensus about what this adapted process looks like in practice, and further work is needed in this area (5, 10).

The final case study in this chapter, Case Study 3.4.3, provides another example of how high quality, ethically conducted research can lead to important findings for Health EDRM.

## 3.4

**Case Study 3.4.3****Delivering on the promise of research: Collaborating with the New York City Fire Department following the 9/11 terrorist attacks**

Past research has shown that people are more willing to participate in research if it is seen to benefit the health system, recovery efforts, or clinical services, rather than be purely experimental. This process relies heavily on trust. Populations affected by disasters have lived through a physically and mentally traumatic experience and may prioritize coping with the aftermath, rather than other activities.

The 2001 9/11 terrorist attacks on the World Trade Center in New York City resulted in 2735 deaths, including 343 firefighters and paramedics who died during the response, over 6000 injured, and countless suffering long term physical and mental health effects (31).

Following 9/11, the New York City Fire Department published early assessments of cancer outcomes associated with the event, which affected federal health care policy, and was eventually translated into cancer being added to 9/11 insurance coverage. New York City Fire Department was also involved in various studies on short and long-term declining pulmonary function in responders. Blood banked following the aftermath of 9/11 has been used to link biomarkers to pulmonary function, potentially predicting susceptibility and resistance to the disease.

New York City Fire Department firefighters had agreed to participate in this research as long as they felt the outcomes were beneficial to themselves or another responder. Maintaining this trust was particularly important in allowing researchers to conduct successful longitudinal studies into the long-term health outcomes of 9/11 responders.

Researchers partnered with the American Cancer Society and the US Centers for Disease Control and Prevention (CDC) to secure buy-in within the community, and found that partnership with these credible organizations was beneficial to the success of the project (32).

**3.4.11 Conclusions**

The goal of health research is to obtain knowledge that will improve health and healthcare and help refine future programmes. For Health EDRM in particular, balancing the pursuit of knowledge with ensuring the safety and wellbeing of participants can be challenging (20).

Ultimately, successful outcomes are dependent on ethical practices throughout the entire life-course of a project, that ensure validity, accountability and sustainability. These are all built on mutual respect between researchers and the communities where the research takes place. It is important that scientific progress, ownership and capacity are retained through the appropriate inclusion of local institutions and communities, that evidence is published for future use, and that learnings are systematically fed back into the community so that they may build evidence-based resilience in the future (15). Experience-sharing will promote robust ethical practices that prioritize participant protection within the complexities of Health EDRM research (5, 10).

### 3.4.12 Key messages

- o **There are ethical aspects to consider throughout the design, review, implementation and publication phases of research that go beyond merely obtaining ethical approval. These considerations help researchers to mitigate against any potential short- or long-term harm to stakeholders in a transparent manner. In addition to evaluating potential for harm alongside scope for immediate benefit, researchers must also take into account the potential broader impact of a project, for example its overall contribution to societal good, capacity to improve livelihoods, the adaptability of knowledge outcomes to benefit other research areas or communities and the potential harm of not filling an evidence gap with high quality research.**
- o **Decisions about the design, implementation or use of research should take into account the value, feasibility and validity of the research question. The added value of research towards addressing an unmet need is necessary to justify the financial, time and human resources that is invested, including the value of missed opportunity in not conducting the research. The feasibility of implementing certain activities within a Health EDRM context must be considered alongside the desirability of completing a research project; and validity must be ensured to avoid unreliable or unusable findings.**
- o **Normative ethical guidelines for research may have to be adapted when operationalized in emergency and disaster contexts due to the unique challenges faced across different areas including security, logistics, time-constraints, or availability of adequate human resources. However, there can be no excuses for bypassing the underpinning ethical or scientific values that ensure research is rigorous and fit for purpose.**
- o **Reciprocal and continued engagement with the affected community is not only key to understanding practical and contextual elements that will facilitate the collection of data and improve the quality of evidence, but is also essential for the development of a respectful partnership in which the participants' interests are not only considered, but protected, especially within the Health EDRM context where the community is made more vulnerable by its circumstances. Outcomes of the research should ultimately be fed back to the community, in order to empower and build capacity, and promote resilience to future disaster or emergency situations.**

3.4**3.4.13 Further reading**

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