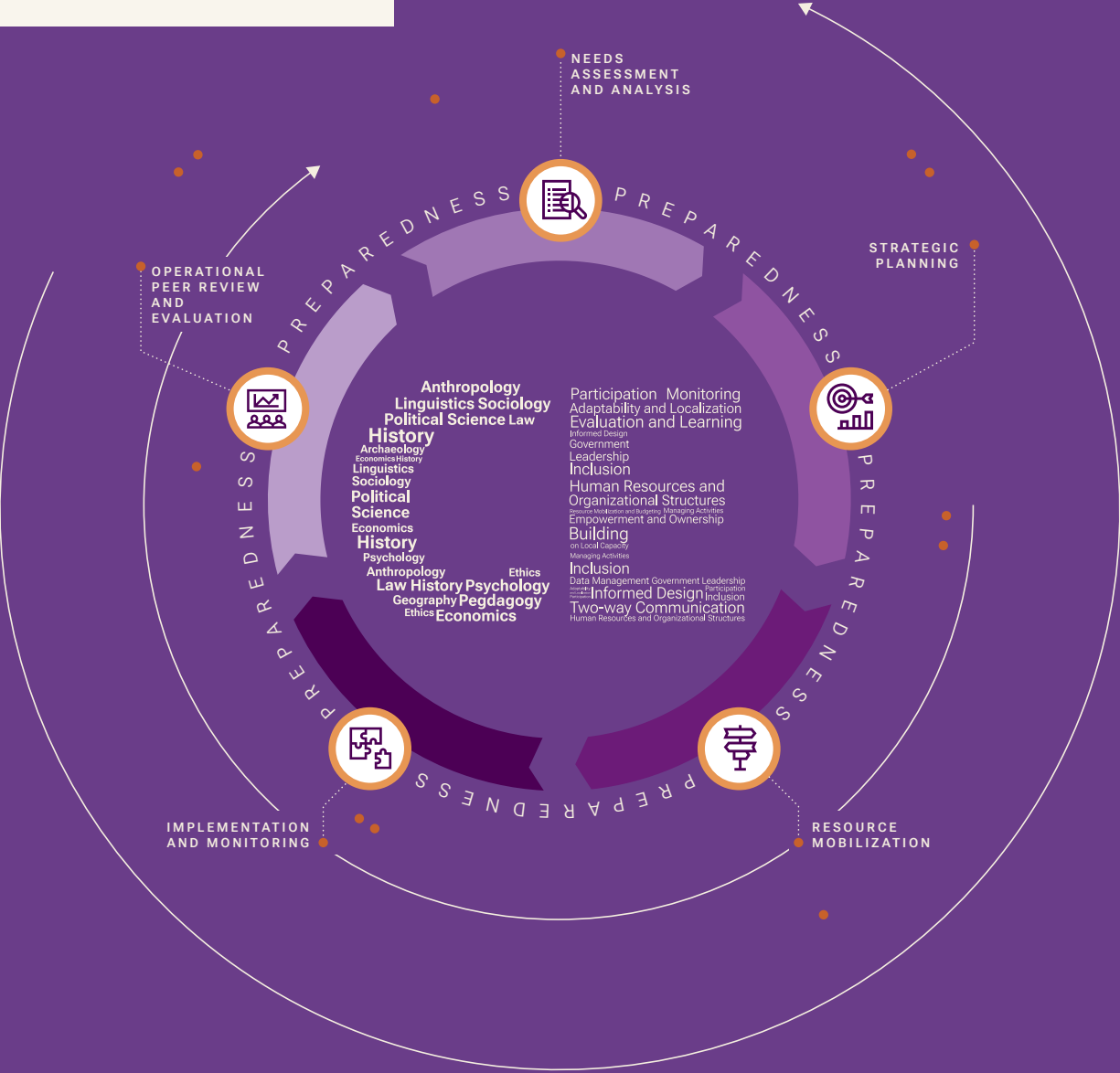


# SOCIAL SCIENCES FOR COMMUNITY ENGAGEMENT IN HUMANITARIAN ACTION

## MAPPING REVIEW ETHICS AND DATA SHARING

### EXECUTIVE SUMMARY



# Social Sciences for Community Engagement in Humanitarian Action **Ethics and Data Sharing Mapping Review**

## **Executive Summary**

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## (Why) ethics and data for SS4CE

Community Engagement (CE) performs a critical and sensitive role in humanitarian action (HA). Avoiding the utilitarian and colonial perspectives on CE in the humanitarian system, we address the contributions of social sciences to interact and co-create recommendations, tools, and practices. The main objective is to support contextual and participatory-oriented approaches to promote better HAs to affected people, and to guarantee a sustainable development progress. An essential ethical aspect of social sciences concerns CE; ensuring the protagonism of affected communities in decision-making processes.

## Challenges to integrating SS4CE in HA

Academic research often operates over long timeframes and, arguably, with a solid political independence; field research, however, needs to be prompt, functional and response oriented. Humanitarian emergencies require timely evaluation and management, especially in crisis contexts where adaptive programming and rapid life-saving actions are required, making traditional ethics reviews impractical. In the perspective of a SS4CE agenda, there is a fundamental gap to be bridged between standard research times and ethical protocols in academic and humanitarian settings.

## General overview of data-related issues in HA

There is a long record of initiatives stating the importance of using evidence and data to achieve humanitarian objectives while protecting personal information. Providing access to, and granting usage of, social sciences datasets containing personally identifiable information, as well as groups and population information collected in humanitarian settings to third parties, presents many challenges. Most prominently, these are related to ethical and legal issues. Regulations applying specifically to humanitarian crises are crucial to establishing consent and placing limits on processing personal data outside crisis contexts.

## Methodology

This first report presents the analysis of the exploratory mapping review on ethics and data sharing for SS4CE in HA, which we conducted from January to June 2022, co-led with UNICEF HQ Social Behaviour Change (SBC) section and the collaboration of a Technical Working Group (TWG) composed of experts in social sciences and HA having specific experience in ethics or data issues. This report is based on different research components; an exploratory review of key research pieces:

1. insights from the TWG1 monthly meetings
2. findings from eight individual interviews with its members, and
3. the approaches adopted were exploratory, constructivist and qualitative in nature.

## Ethics in HA

Humanitarian aid is regulated by multiple sources of obligations. However, due to the complex nature of the operating conditions, where resources and time are limited and humanitarians operate under multiple stressors, it can be extremely difficult to apply ethical principles. For all types of decisions, individuals on-field need to receive adequate 'ethical literacy' and to be oriented and held accountable by up-to-date norms to make informed ethical choices. HA has also been the object of fierce ontological or punctual critics. Scholars have notably questioned its purpose and means, as an emanation of global North powers, as well as the underlying politics of life whereby humanitarians, particularly expatriates, derive higher protection and privileges on the field by virtue of their engagement.

## Data sharing and data responsibility in HA

The risks associated with social sciences for community engagement in data sharing are several:

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### Collection of 'sensitive' data and data extracted from social media

Since humanitarian organizations intervene in situations with populations that are highly fragile, and in high-risk settings that frequently don't allow for input or don't demand for declared

consent to each step, the absence of technical and ethical standards could result in harm to these populations. It is crucial that data sharing procedures have categorized levels of sensitive data, as well as attention to specific national laws and regulations about data protection, which must be obeyed at the local level.

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### Data retention storage

Data should be retained for a defined period (e.g., three months, a year) for each category of data or documents; it is not stated how long a database is useful and relevant. Data retention requires a high level of data and computational literacy that is highly limited and frequently underfunded in conflict areas. It is important to have internal assurances as to when data has been deleted, that it has been deleted from shared systems and that the same action has been carried out by any third parties that received the data.

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### Secondary use of data

In HAs secondary users may repurpose the data. Not only does this use diverge from the original intentions of collection, but the rich contextual dimensions of social sciences data may also be completely erased in this reuse. De-identification of ownership of data can be problematic when it is necessary to identify missing or deceased people, as often occurs during wars, migration and political conflicts.

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### Data ownership and Data sharing

It appears that there may be a lack of clarity over data ownership at the very least for the populations among which the data are collected. Data sharing can take place through formal and informal channels and data flows can be 'leaky', in the sense that actors and structures in this humanitarian 'ecosystem' are multiple, and data can be controlled, accessed, shared or stolen.

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### Is there an implementation gap

The structures, guidelines, and calls for action on data sharing in HA are many, and yet, our interviews and collective discussions have underscored a deep lack of satisfaction with the current situation.

## Synthesis of the main topics emerging from interviews and TWG meetings

In the mapping review, the research team found that existing ethical and data management principles, regulations and guidelines are challenging in their application to HA. The lack of applicability of existing complex regulatory frameworks highlights the need to elaborate adequate, implementable global standards, in the form of guidelines, tools, checklists and templates, to collect, store, use and share data for humanitarian purposes. Ethical requirements should encompass all aspects of HA, from in-the-field research to the way the CE process is carried out by humanitarians on the ground.

## Main findings by theme

The interviews and TWG meetings reveal that there are many challenges regarding ethical and data sharing in HA:

- 1. A lack of comprehensive, high-quality baseline data** to inform responses and to include key actors on the ground, because is not always available and robust, as comprehensive, response-oriented data collection rarely takes place in the preparedness phase.
- 2. A need to adapt to diversity of humanitarian actors;** each of them needs to be provided with an applicable definition of rules, functions and responsibilities for data collection, processing, storage, preservation, access and sharing in, and beyond, operational contexts.
- 3. A need to adapt to the type and context of crisis,** which should be addressed by actors on the ground to make an ethical framework implementable, useful and operational in every emergency response by attaining a satisfying level of standardized contextualization.
- 4. Logistical and time-related challenges of ethical regulations in HA;** because in the context of humanitarian emergencies, data collection should respond to the vital interest of individuals at risk, contrary to the principles of conducting social research where the generation of knowledge is the main reason.

## Dealing with the specificity of ethics for SS4CE in HA

A set of limited guidelines for social science research in HA can be found across different documents, although they are often undetailed, scattered and incomprehensive. Social sciences have taught that it is necessary to clearly describe the methodology implemented to ensure that research adheres to ethical criteria. It also needs to include a diversity of actors, as a way of triangulation, to validate information which can be helpful in avoiding bias that reproduces asymmetries. Common ethical guidelines should be framed from a perspective that ensures social sciences application are being used to benefit affected or at-risk communities, among other aspects, by respecting their ownership over their personal and community data. Power dynamics influence not only the relation between humanitarians and communities, but also between donors, researchers and humanitarian institutions across the humanitarian architecture. It is also important to understand how power relations shape internal community dynamics to ensure no one is left behind. These dynamics are reflected in the nature and implementation of this report as well as its scope, how the information is managed, who has control over it and also with whom it is shared. *Specific proposals: creating a HA ERB, building up capacity, connecting and strengthening existing national or organization-based ones*

The role of this ERB should be to ensure social sciences applications respect humanitarian and social justice principles, as well as communities' independence and human rights and developing compliance mechanisms and relevant procedures to be implemented in case of breaches. However, there are concerns regarding the logistical, financial and time-related challenges related to the creation, support and maintenance of such a body.

## Main Analytical Categories

### Asymmetries

At least two types of asymmetries can emerge during data collection:

1. Information asymmetry, and
2. asymmetries in the ethical research parameters.

In a situation where data subjects have no choice about giving their personal data – whilst saving their lives – they have no control about how their data will be used in the future. In this framework, the humanitarians must deliver full attention about data security and, with good management, may follow recommendations about how to handle this responsibility.

### Data Ethics and Ethics of Data

HAs and research in the social sciences follow different paths with how they observe data ethics, yet these paths can meet in some circumstances. The data collected by social scientists, within academia, brings sense and meaning to the research, allowing conclusions to be achieved. In the case of HAs, data is collected, recorded, transcribed and stored during activities completely dependent on what can be done in an emergency.

Ethical data that may emerge from data collection, carried out in emergency situations, should be shared subject to reservations regarding future uses as secondary databases. This sharing must follow regulations, guidelines and security parameters recommended and legislated by the current data governance.

These are the key points to keep in mind when developing guidelines:

1. Social Sciences are always about people, society, culture and context; the ethics of the vulnerable and the vulnerability of ethics regulations; ethical code is necessary but not sufficient; ethics needs to be extended to operational data management, operational use of technology; from an ethical perspective, balancing decisions based on available data are required to avoid bias or exclude less visible populations; and
2. data subjects (or victims) should be at the centre of a humanitarian emergency.



## Community Engagement

It is important to understand what the objectives of CE at the different stages of the HPC are, in connection with the different sectors specificities and stakeholders' mandates and roles in HA. The Minimum Standards aims to support "implementation of high quality, evidence-based community engagement in development and humanitarian contexts" (UNICEF, 2020). It provides relevant indicators; however, the operationalization remains unclear, and contextualization is open to interpretation.

CE can be systematic in Western thought, but this is not universal. It is fundamental to acknowledge the way it is understood and internalized by concerned communities around the globe. The intersection of these systems of knowledge and practice will eventually define the way CE will be implemented in each specific context and moment. We promote a formulation whereby CE would entail making the different affected communities' co-holders, and not just recipients, of power. When embedding this working definition in the realm of HA, we can assess the variety of approaches and initiatives taken to engage communities with a series of analytical benchmarks.

Data management issues would have to comply as well with our working definition of CE, and our vision of social sciences application, in ensuring the community is a co-holder of power and therefore has decision-making power over which, how and for what purpose their own data is collected, managed and shared, especially in third contexts. Addressing these challenges about the operationalization of CE in HA could foster the collaborative enhancement of the relationship between communities affected by humanitarian crises and social sciences application in the different stages of the HPC. This closer collaborative work will improve both HA and the application of social sciences, revisiting the role and status of affected communities and their ownership over the structures and resources at stake in humanitarian programming and implementation – of which data is only a part.

## Conclusions

Until this stage of the investigation, we could observe that, as a member of TWG1 said; "ethics is ethics wherever ethics are being applied". That is completely true, but whether ethical recommendations will be followed depends sometimes on the framework that the humanitarians or researchers are facing. Additionally, it also depends on the expertise of the person that is enrolling people and collecting subjects' data in the field. At the same time there are common points and possible clashes between research ethics and humanitarian ethics, and they should be explored and analysed. The understandings, rules, regulations and ethical standards are based in Western perspectives from the global North institutions and values that are implicit of racism and unequal power dynamics. How can the application of social sciences for CE in HA contribute to the decolonization of both research and HA? What should be part of ethics guidelines and mechanisms that reflect this aim, translated into material actions?

The challenge is to build a global good – a guideline on ethics and data sharing for social sciences application for CE in HA – that is applicable and useful to humanitarians, inclusive of ethical research rules, regulations and security parameters, and local knowledge and experiences around these values to pragmatically support decision making in a power-balanced, non-racist manner.

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in Humanitarian Action**

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