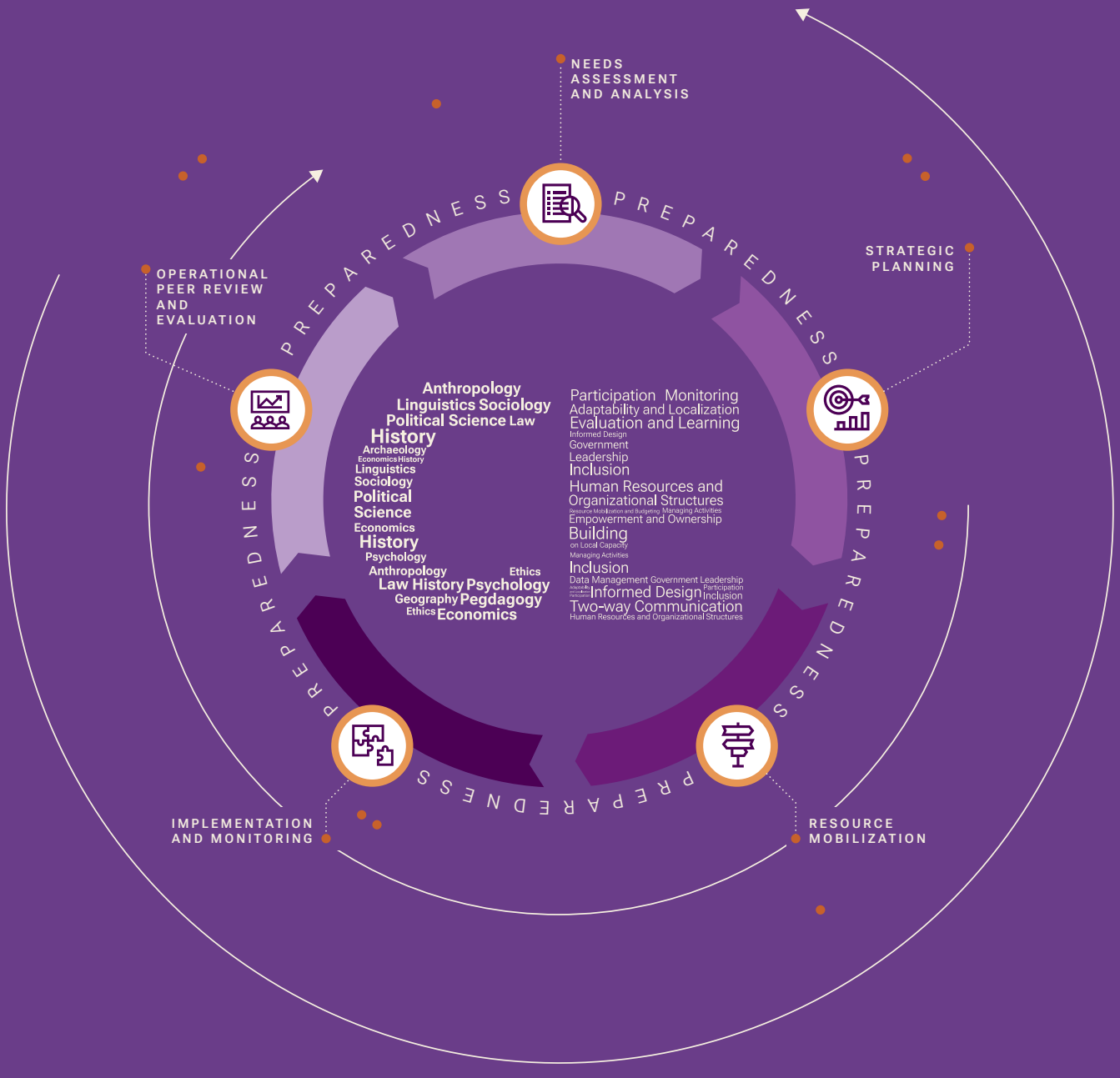
SOCIAL SCIENCES FOR COMMUNITY ENGAGEMENT IN HUMANITARIAN ACTION

MAPPING REVIEW ON ETHICS AND DATA SHARING



sonar global

SS CE
Connecting Community Engagement with Social Science in Humanitarian Contexts

Ministério da Saúde
FIOCRUZ
Fundação Oswaldo Cruz

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

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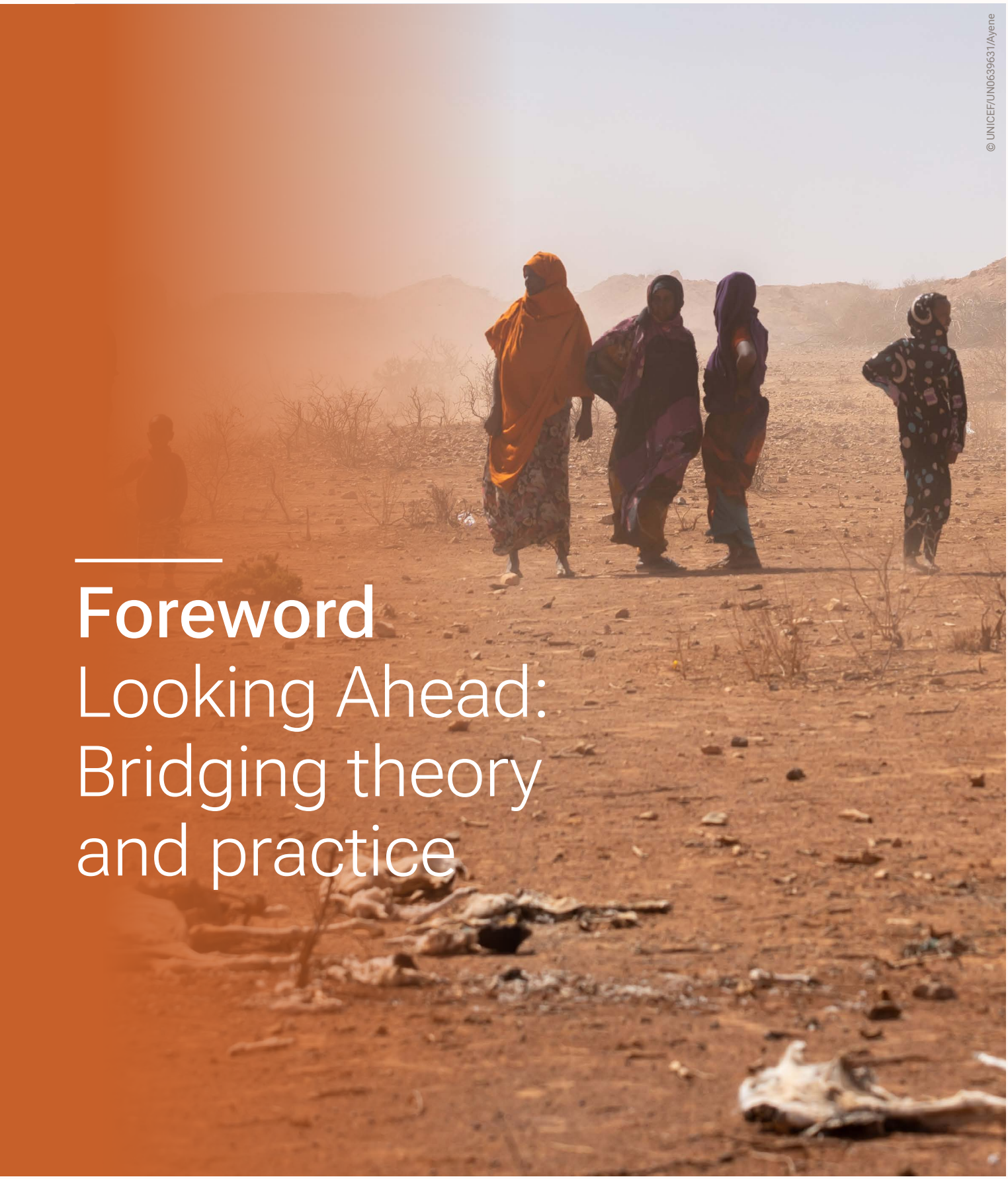

Foreword
Looking Ahead: Bridging theory and practice

Social Science for Community Engagement in Humanitarian Action Project (SS4CE in HA) is an initiative launched at the end of 2020, funded by the Bureau of Humanitarian Affairs, USAID. The main objectives focus on co-creation of global goods, designed as a collaborative approach that connects with global humanitarian and public health system-wide existing mechanisms that harness active participation of humanitarian organizations, academic institutions and donors. The processes undertaken for the development of global goods are also further framed in the 'decolonization of aid agenda' and provide clear recommendations for the implementation of actions that drive people-centred and community-led humanitarian and development programs. As envisioned, the project has made substantive progress towards systematically aligning social science informed community engagement actions to humanitarian architecture, tailored to different elements and enablers of the humanitarian program cycle (HPC).

Leveraging on the initial, exclusive public health emergency (PHE) focus at the time, due to the COVID-19 response,the SS4CE project developed a multi-pronged,governance structure that could facilitate the linkages and inform all humanitarian crises (e.g., natural hazards, conflicts and PHEs). This governance structure provided technical oversight to the development of SS4CE global goods, as well as positioning the processes and outputs of the project with key humanitarian stakeholders including the Inter-Agency Standing Committee (IASC), Core Humanitarian Standard (CHS), Clusters and committees, for the uptake and mainstreaming within the ongoing and relevant humanitarian program processes.

The **mapping of ethics for the application of SS4CE in HA** was conducted through a partnership with Sonar-Global, the Oswaldo Cruz Foundation (Fiocruz) of Brazil and members of Technical Working Group-1 (TWG-1). This analysis was envisioned to review existing ethics guidelines and approaches currently applied in the humanitarian system and academic world, related to social sciences and community engagement in humanitarian action (HA). By reviewing the content of identified guidelines and literature it challenges the status-quo of humanitarian programmes, wherein at risk and affected communities' engagement continues to be notional and reinforces capacity gaps to engage communities in their social-cultural realms. This underpins the necessity to have increasingly adaptive HA that is contextually specific, sensitive to vulnerabilities and power relations, and planned in consultation with at risk and affected communities and local institutions based on social, and interdisciplinary, science evidence. Community engagement, informed by social sciences, addresses participation issues and the immediate needs of the affected communities but also strengthens community systems where marginalised groups become equal partners in finding solutions, having wider knowledge and understanding of social science disciplines' conceptual frameworks (e.g., historical, political, sociological, economical) and providing pathways to deal with systemic fallacies and challenges (i.e., social justice, gender equity, decolonization and localization).

We hope that this mapping exercise will contribute to evolving and identifying actions to reform community engagement processes, especially leveraging the spectrum of social sciences in challenging humanitarian contexts. The report identifies gaps that should be addressed and included in ethics guidelines for the application of SS4CE in HA, bridging the gap between what is existing and what is needed for ensuring communities are at the centre of humanitarian processes and programmes. This will be of utmost importance to respond effectively in current and future crises.

Sonar Global, Tamara Giles-Vernick
UNICEF, Vincent Petit

Key deliverables for the project are:

- Landscape report
- **Ethics and Data Sharing Mapping Review**
- Codes of Conduct Mapping Review
- Mapping of Capacity Development for the application of SS4CE in HA in Conflicts and Hazards
- Common Monitoring and Evaluation Framework for Community Engagement
- Compendium of Case Studies on the Use of community engagement to Inform Decision Making
- Desk Review of Community Engagement Iindicators Across Humanitarian Response Plans (2022) and Documentation on Community Engagement
- Vision Paper on Community Engagement for Accountability to Affected Populations and Social and Behavior Change.
- Common Principles and Code of Conduct for the Application of SS4CE in HA

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Executive Summary

(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:

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.

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.

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.

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.

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.

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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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Acknowledgments

We want to sincerely thank everyone who contributed to this research process in what was unmistakably a shared effort. We thank all TWG-1 members who participated in the co-constructive dialogue process through meetings and individual interviews. We are grateful to the Strategic Advisory Group (SAG) for the project members for feedback on findings.

The research was made possible by the funding of USAID BHA, and the program support of UNICEF Social and Behavioral Change Section, Sonar-Global, the Oswaldo Cruz Foundation (Fiocruz) and Institute Pasteur.

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List of Abbreviations

AAP	Accountability to affected populations
AFRO (WHO)	Africa Regional Office (WHO)
BHA	Bureau of Humanitarian Affairs
CE	Community Engagement
CHS	Core Humanitarian Standards
CoC	Code(s) of Conduct
DRRM	Disaster Reduction and Risk Management
ERB	Ethical Review Board
EVD	Ebola Virus Disease
HA	Humanitarian Action
HPC	Humanitarian Programme Cycle
IASC	Inter Agency Standard Committe
ICRC	International Committee of the Red Cross
IEC	Independent Ethics Committe
IFRC	International Federation of Red Cross and Red Crescent Societies
INGO	International Non-governmental Organization
IRB	Institutional Review Board
MSF	Médecins sans Frontières
NGO	Non-governmental Organization
OCHA	UN Office for the Coordination of Humanitarian Affairs
PHE	Public Health in Emergencies
RCCE	Risk Communication and Community Engagement
RDC	Republique Democratique du Congo
SBC	Social and Behavioral Change
SOP	Standard Operating Procedure
SS4CE in HA	Social Sciences for Community Engagement in Humanitarian Action
TWG	Technical Working Group
UNCST	Uganda National Council for Science and Technology
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization

Introduction

This mapping review on ethics and data sharing for the application of social sciences for community engagement in humanitarian action (SS4CE in HA) explores how social sciences contribute to processes of interaction and co-creation of existing ethics and data sharing practices and tools with affected and at risk communities. The main objective of this mapping exercise is to review existing guidelines and literature on the topic, aiming to determine the main gaps and challenges for the systematic integration of SS4CE in HA, by critically reflecting on utilitarian and colonial perspectives of how CE is currently integrated in HA. An essential ethical aspect of social sciences concerns CE, ensuring affected and at risk communities are part of decision-making processes. CE is a key element, requiring a variety of political and institutional relationships which need to be adequately ascribed to different social, political, and cultural contexts. Stakeholders such as donors, academics, humanitarian practitioners and representatives from affected and at risk communities, among other HA-involved actors, need to ensure that crisis-affected places, populations, groups and individuals receive the assistance and protection they need without amplifying or replicating misrepresentation, discrimination, power asymmetries, colonial dynamics, racism and violation of human's rights.

There were several core considerations established, at inception, to guide this mapping review on the form and content of existing guidelines and documents on ethics for the application of SS4CE in HA. Throughout the mapping review the focus was placed on understanding perceptions and experiences, as well as accumulated knowledge from social scientists, academics and humanitarian practitioners who deal with the complex dynamics of data collection, processing, analysis, and dissemination of (individual or pooled) information in HA.

This report presents the analysis of the exploratory mapping review on ethics and data sharing for SS4CE in HA, conducted from January to June 2022. The mapping review process was carried out in consultations with TWG1 members, both in monthly meetings and in-depth interviews, complemented by the review of literature and documents. It should be noted that participants in TWG1 were formally invited to participate in the technical working group, to acknowledge their time and technical contributions to the outputs of this project, and future opportunities for uptake and advocacy of the recommendations and global goods.

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, because significant investments are required to set up an effective infrastructure and to recruit specialised personnel for responsible data management and data governance. 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 organic or facilitated CE process is carried out by humanitarians on the ground. Therefore, the scope of this assessment aims to reflect on existing ethics practices with an alternative purview throughout humanitarian interventions. This includes considering operational data management and the operational use of technology across humanitarian clusters and current practices, in which capacity and skills should be consistently applied and uphold ethical issues, and where they need to evolve.

This report provides insights and reflections on the gaps, the challenges, and the opportunities of social sciences contributions as foundational for the integration and implementation of community engagement during HA through adequate ethical and data sharing principles. The mapping will inform a second objective, to knit together these principles in the form of a global good that is inclusive of local idiosyncrasies, that can be operationalised by stakeholders across the humanitarian architecture.

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Methodology

This report is based on different components; (i) an exploratory review of key research pieces; (ii) insights from meetings of a TWG composed of academics and practitioners with expertise in social sciences and community engagement during HA TWG1 meetings; and (iii) findings from eight, individual interviews with its members from the TWG. The approach adopted was exploratory, constructivist and qualitative in nature.

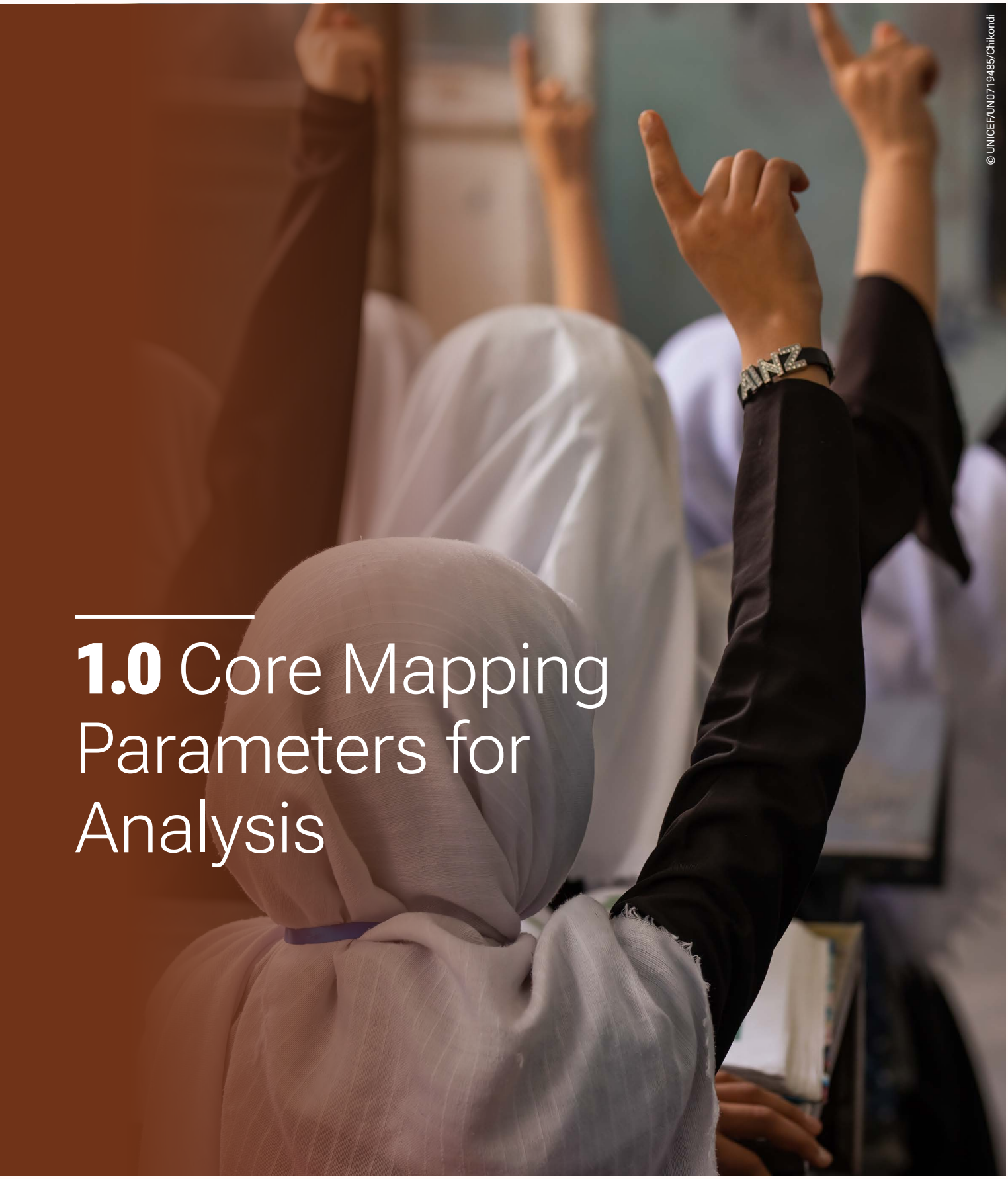
i. The exploratory review of literature focuses on analysis of key guidelines and documents related to ethics and data sharing in the social sciences, community engagement, and humanitarian studies domain as well as in the humanitarian system (from different UN agencies, the Red Cross movement, NGOs, etc.) to draw a state of the art and map the key terms, most prominent debates and challenges and best practices in these areas.

ii. The TWG1 monthly meetings offered an essential platform to routinely collect and discuss different opinions and experiences of members around emerging issues, challenges, and opportunities. These meetings helped steer the research process by suggesting new sources to review or other aspects to be considered. The research team consistently communicated with TWG members to explore how social scientists and humanitarian practitioners understood, experienced and expressed relevant aspects related to the research key topics. This constant exchange with this advisory group allowed the team to grasp the latest developments and current topics and challenges to better define priorities and shape the project's next steps.

iii. Individual interviews conducted with the aim of mapping the personal knowledge and experiences of members related to ethics and data sharing for SS4CE in HA, and to identify gaps, challenges and opportunities.

The following section explains the main elements considered in this mapping exercise; the humanitarian programme cycle, social sciences in HA and community engagement in HA. All sections include the preliminary findings from the TWG1 discussions and interviews, as well as the analytical categories emerging from the mapping exercise, with the aim to:

- Identify social sciences' current and possible contributions to HA.
- Recognise ethical issues related to social sciences' application, data management and data governance, and how they link with CE in HA.
- Highlight the main gaps and challenges to improve CE through social science integration in HA.



1.0 Core Mapping Parameters for Analysis

1.1. The Humanitarian Programme Cycle

The SS4CE project works with the Humanitarian Programme Cycle (HPC).[1]

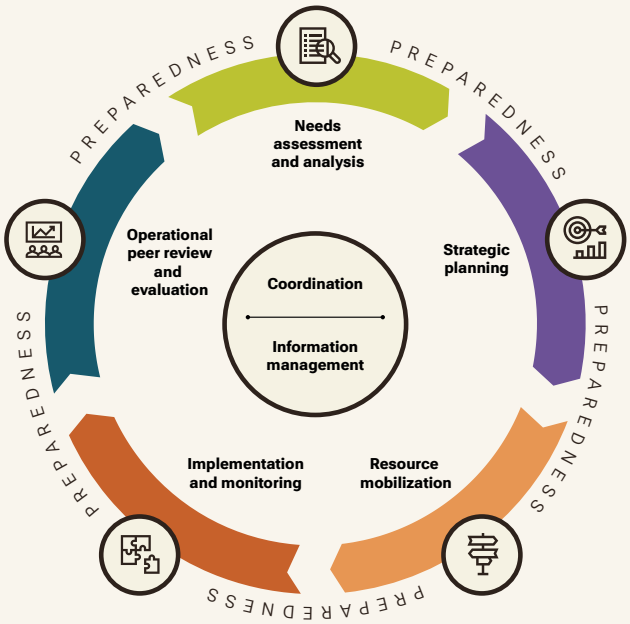
For the purpose of reviewing the application of ethics and data sharing it was critical to consider that different stages in the HPC have distinctive operational modalities and priorities, across different actors and stakeholders. Gaps and needs are expressed at multiple levels, including by social scientists working in academia or on the ground, by humanitarian practitioners including local professionals, as well as by community representatives or networks, considering different stages of the HPC, during humanitarian response but also for preparedness and early recovery. The application of social sciences should be adapted and fit for purpose in all stages of the HPC. Similarly, at risk and affected communities have their own understandings of an emergency or crisis which should be considered at all stages of the HPC.

1.2. Social Sciences in HA

Social sciences can contribute to enhance participatory approaches and improve coordination of local and global humanitarian action. Consequently, social sciences integration can strengthen and, to some extent, change the ethics of HA by actively recognizing and working with the central role of at risk and affected communities, their knowledge, priorities, and objectives. Social sciences also show how crises have a dissimilar impact on different groups, rendering them more vulnerable, exacerbating inequities, making sure those groups are visualised and cared for. Leveraging social sciences' knowledge for improving CE is critical to tackling structural issues and to inform discussions on power imbalances, historical racism in the relationship between Global North and South, Eurocentric knowledge dominance (self-considered to be 'global'), and knowledge dominance from a decolonial perspective, by integrating diverse forms of knowledge and experience ensuring the participation of at risk and affected communities in HA.

Box 1: The Humanitarian Program Cycle (HPC)

The SS4CE in HA project seeks to advance CE through the integration of social science in all stages of HA, i.e., in all stages of the Humanitarian Program Cycle (HPC). The HPC is a tool to facilitate the preparation and provision of humanitarian assistance through five consecutive phases: (i) needs assessment and analysis (i.e., conducted collaboratively with all relevant actors, including from the local and community level); (ii) strategic response planning (i.e., the creation of management tools and strategy plans); (iii) resource mobilisation; (iv) implementation and monitoring; and (v) operational review & evaluation (i.e., both independent and internal assessment). Moreover, the HPC aims to foster accountability, funding, a focus on the vulnerable and a needs-based approach (OCHA, n.d.).



1 https://www.humanitarianresponse.info/en/programme-cycle/space

1.3. **The constructs of community and engagement**

From a linguistic perspective, CE is a polysemic term, which constitutes both its strength and its weakness. While it can serve as a comprehensive key term for multiple approaches across multiple domains, the shape, modalities, temporality and depth of such engagement, as well as what is intended as community, can vary significantly depending on the intentions and mandates of the stakeholders taking part in the process, and the social, political and power dynamics influencing their relationship. When getting lost in the ambiguity of the term, we run the risk of depoliticizing and flattening a series of real-life interactions which are intrinsically characterised by political, hierarchical - and eventually power-related - tensions.

This statement seems to be valid for all the different disciplines mentioned at the beginning of this section. If we consider CE in public health, in urban studies, or any of the aforementioned disciplines, we can identify a pattern whereby a holder of power in the form of knowledge (e.g., a public health expert delivering a risk communication intervention), resources (e.g., a town hall designing social mobilization projects to consult local youth on initiatives to address issues in a difficult neighbourhood), socio-political status (e.g., social scientists divulging their research in a presentation addressed to lay citizens) is involved in the task of engaging lay publics, or a specific population such as a community, by making them the recipient of some part of this power, whatever its nature. Accordingly, engagement can range from sensitization and risk communication campaigns to community participation and community mobilization, to involvement in agenda-setting and community leadership.

The concept of community also deserves some consideration. Community usually refers to a group of people united by a set of features. Questioning who the communities we are referring to, when conceptualizing CE in HA, is a crucial first step. The core humanitarian principles of humanity, impartiality, neutrality and independence extend the scope of the imperative to save lives, deliver assistance and offer protection to all affected people in a crisis-torn area. This is the arena where the different communities will be identified, inclusive of the humanitarian community. How this plays out in practice in the middle of crisis response is shaped by several factors related to logistical issues, the invisibility of marginalized groups and individuals in the community in times of crisis, as well as to the specific mandate of the agency or organization delivering assistance that shapes its contacts with the local community. The volatility and complexity of the situation makes the task to reach all individuals in a community challenging.

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1.4. **Community Engagement in HA**

The diversity of perceptions and applications of CE, from a humanitarian actors' angle and from the social sciences' angle, presents many challenges to find common ground for a collaborative relationship. Bridging these perceptions and strategies at the different stages of the HPC is a big task. However, social science methodology could significantly contribute to improving HA effectiveness and efficiency, facilitating affected communities' engagement processes at all stages of the HPC.

Ethical dimensions must be considered when applying CE from both angles. 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 landscape of CE literature is wide and covered by multiple disciplines, ranging from environmental studies, communication studies and translational research to public health, urban studies and HA. For HA, the UNICEF Minimum Quality Standards and Indicators for Community Engagement is used as a reference, where CE is defined as:

> ***A foundational action for working with traditional, community, civil society, government, and opinion groups and leaders; and expanding collective or group roles in addressing the issues that affect their lives. Community engagement empowers social groups and social networks, builds upon local strengths and capacities, and improves local participation, ownership, adaptation, and communication. Through community engagement principles and strategies, all stakeholders gain access to processes for assessing, analysing, planning, leading, implementing, monitoring, and evaluating actions, programmes and policies that will promote survival, development, protection, and participation.***

The Minimum Standards is an important document for CE in HA in that it aims to support "implementation of high quality, evidence-based community engagement in development and humanitarian contexts" (UNICEF, 2020). IT covers three main aspects in HA:

i. implementation
ii. coordination
iii. integration

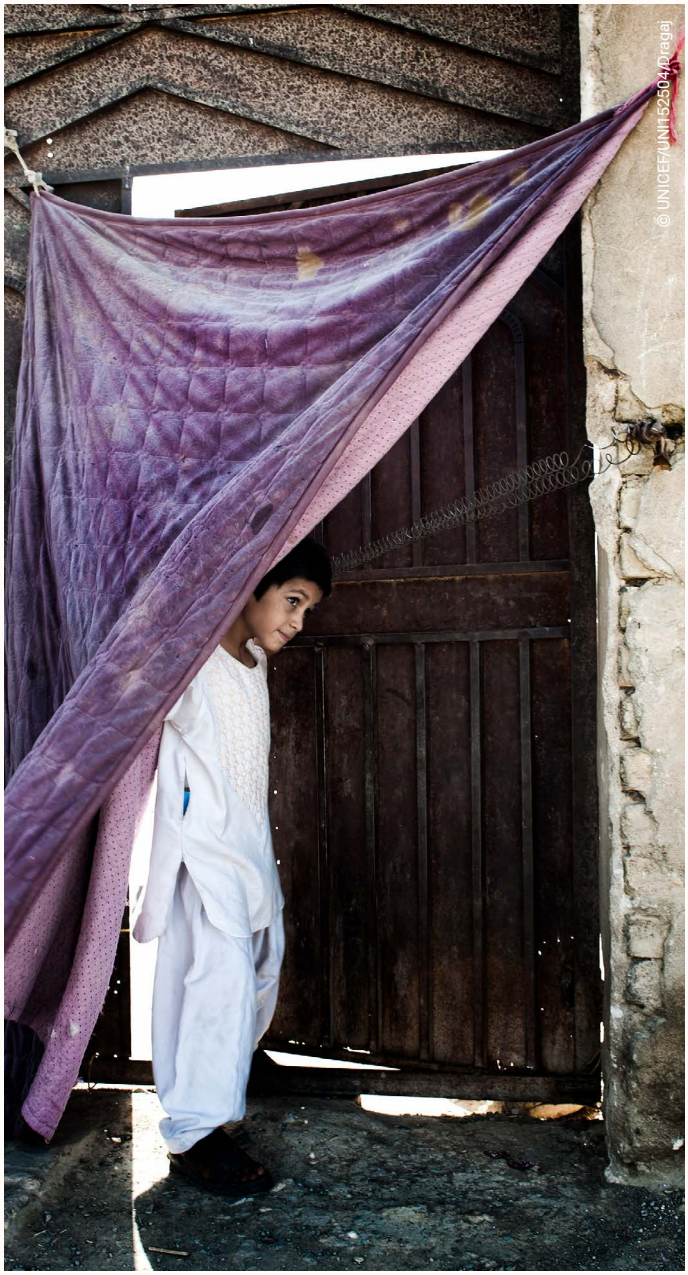
These aspects are based on six core standards (principles):

i. Participation
ii. Empowerment and Ownership
iii. Inclusion
iv. Two-way Communication
v. Adaptability and Localization
vi. Building on Local Capacity.

The document outlines several guidelines on the collection, management, use and sharing of data in humanitarian interventions. It looks specifically at CE data with a focus on data concerning local cultural, social and political contexts.

While The CE standards and indicators provide relevant guidance, the operationalization and adaptation, during the different phases of humanitarian interventions, is required. The document refers generally to data without addressing in, detail, how to deal with the specificity and sensitivity of social science data and the issues related to their collection, processing, anonymization, analysis, use, sharing and storage, as well their overall management in view of the time, financial and logistical constraints of a humanitarian intervention. Contextualization in the application of these standards remains open to interpretation, regarding how standards must be prioritised, internalised, and implemented in different scenarios depending on the organisation's mandate, the region or country of operation, the type of crisis, and the nature of the intervention. The boundaries of what we could define as 'CE data', as well as the matter of which ethical guidelines should organizations comply with in collecting and managing data, remain unaddressed or scarcely addressed.

These limitations of institutional application of CE mirror a wider concern; the limited operationalization of both the CE component of HA and the contributions that the social sciences can bring to complement, strengthen, and improve such components. This can be seen in the absence of specific guidelines on their data ethics implications. This need for institutional adaptation should provide clarity for programming, budgeting and implementation procedures concerning SS4CE data collection and management. However, this absence of compliance mechanisms, deepens the gap between general policies, guidelines and principles, and their application in HA.



1.5. The integration of CE in HA and SS4CE in HA

If CE is considered as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people",[2] the positionality and purpose of actors engaging in this collaborative work should nevertheless be questioned. As shown previously, the process of engagement is to some extent described as a top-down relationship where the community reached may not represent the totality of the local population. Moreover, implementing CE can be systematic in Western thought, but its conceptualization is not universal. It is fundamental to acknowledge the different ways in which 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. The standards and principles regulating CE application in HA, as in other fields, require it to be adequately oriented and clarified to ensure that it takes place in respect of ethical, humanitarian and social justice principles, inclusive of local understandings of these concepts, and that it does not reproduce the asymmetries discussed above. The application of social sciences is key to understanding those localised ways of perceiving CE, the crises itself and the humanitarian response.

Reflecting on these considerations, 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. Exchanges with local groups in HA take place at all levels. Humanitarian actors need to gain local people's trust and support to ensure joint development and delivery of effective interventions, but not all these exchanges fulfil the conditions for a substantive participation of local communities in programming. The expression Accountability to Affected Populations (AAP), a principle of accountability translated into practices and systematized in the humanitarian architecture, has been a way to involve communities in a substantive but also instrumental way, due to its ambiguity serving the humanitarian system and at the same time aiming to contextualized operationalization. Participatory approaches can range from involving communities in agenda setting to collecting their feedback without translating it into a change in action.

When focusing on the application of social sciences in the different stages of the HPC, we see a comprehensive lack of consensus concerning the guiding principles underpinning its involvement. This is particularly true of CE but can be seen throughout HA. This has translated into a variety of approaches, methodologies and applications deployed in the field. These approaches can range from rigorous participatory action research, informing strategy related and material changes in programming, to a 'tick the box' approach where findings from surveys or focus groups discussions are used to endorse current programs. These findings can also be 'forgotten', or not prioritised, when suggesting uncomfortable changes and are limited to be used for publications without impacting in any positive way the situation of at risk and affected communities or only shared in one-off meetings with the local community at the end of interventions. These approaches mean that community data is rarely defined, collected by, or made available to the community itself to strengthen its capacities, build local repositories and inform changes. Rather, data largely remains property of agencies and organisations who determine its use.

This understanding of the constructs of social science and CE allows us to explore to what extent, and where, the social sciences can play a role in defining the ethics of CE in HA and how CE in HA can have a role in influencing the application of social sciences. Data management issues would have to comply with this working definition of CE and likewise this 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 (e.g., for displaced/ refugee populations).

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 at risk and affected communities and their ownership over the structures and resources at stake in humanitarian programming and implementation, of which data is only one part. Applying ethical recommendations from the social sciences to HA and integrating humanitarian 'ethically conscious' social science contributions in HA, grounded in appropriate knowledge of the transience and functionality of the HPC, is crucial to reach CE understandings, approaches and activities that speak to all stakeholders (including at risk and affected communities) as well as to contribute to systematize the operationalization of stronger, equal, effective social, cultural and political contextualization of humanitarian interventions.

1.6. **SS4CE in HA: A stronger focus on at risk and affected communities**

To be effective and ethical SS4CE needs to be designed so that research and/or operational data collection processes (i.e., research design, data collection strategies), and the analysis and use of collected data, contributes to humanitarian outcomes and at risk and affected communities' needs. The systematic inclusion of SS4CE makes HA more accountable to at risk and affected communities and more aware and respectful of their cultural, social, and political context. At the same time, the application of SS4CE in HA provides at risk and affected communities increased capacity to effectively uphold their rights by participating in humanitarian efforts and its organization. It is crucial to engage with at risk and affected communities, and be clear about the purpose of that engagement, for collecting their data. Implementing co-creative processes ensures at risk and affected communities can validate and use these datasets for their own purposes, and decide where, how and with whom the data is to be shared. Poor collection practices, improper data sharing, and the misuse of primary and/or secondary data may place individuals or entire communities susceptible and jeopardise HA.

Faced with weak government protection and sometimes threatened by government systems, fragile or failed governance, disrupted health and other social sector systems, insecure living conditions, unsafe water sources and food insecurity, crisis-affected communities can be at risk of inadequate consent processes and coercion. Vulnerability in humanitarian emergencies is the result of class, gender, age, ethnic, racial, able-bodied, and religious inequalities, and hierarchies that prevent the individual from satisfying basic needs, accessing resources, and exercising their rights. A social-historical approach, for instance, allows for the comprehension of historical structures that disseminate, promote, and enforce the marginalization of specific groups, creating and/or perpetuating vulnerabilities.

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1.7. **Challenges to integrating SS4CE in HA: Preparedness and Response**

The review works with the HPC (see p.4) and the different stages to characterise the application of SS4CE and the correspondent ethics and data sharing regulations linked to this application. The application of SS4CE in HA calls for timely assessments that contribute to bridge the current humanitarian system with different knowledge structures and ethics values. Humanitarian action, mainly in the response phase where life-saving actions are implemented, needs to be prompt and fit for purpose. At the same time, ethical review processes for academic research require long time frames. The fast operational speed during responses makes traditional ethics reviews impractical. There is a fundamental gap to be addressed between standard research times, ethical and data sharing protocols in academic settings and in HA.

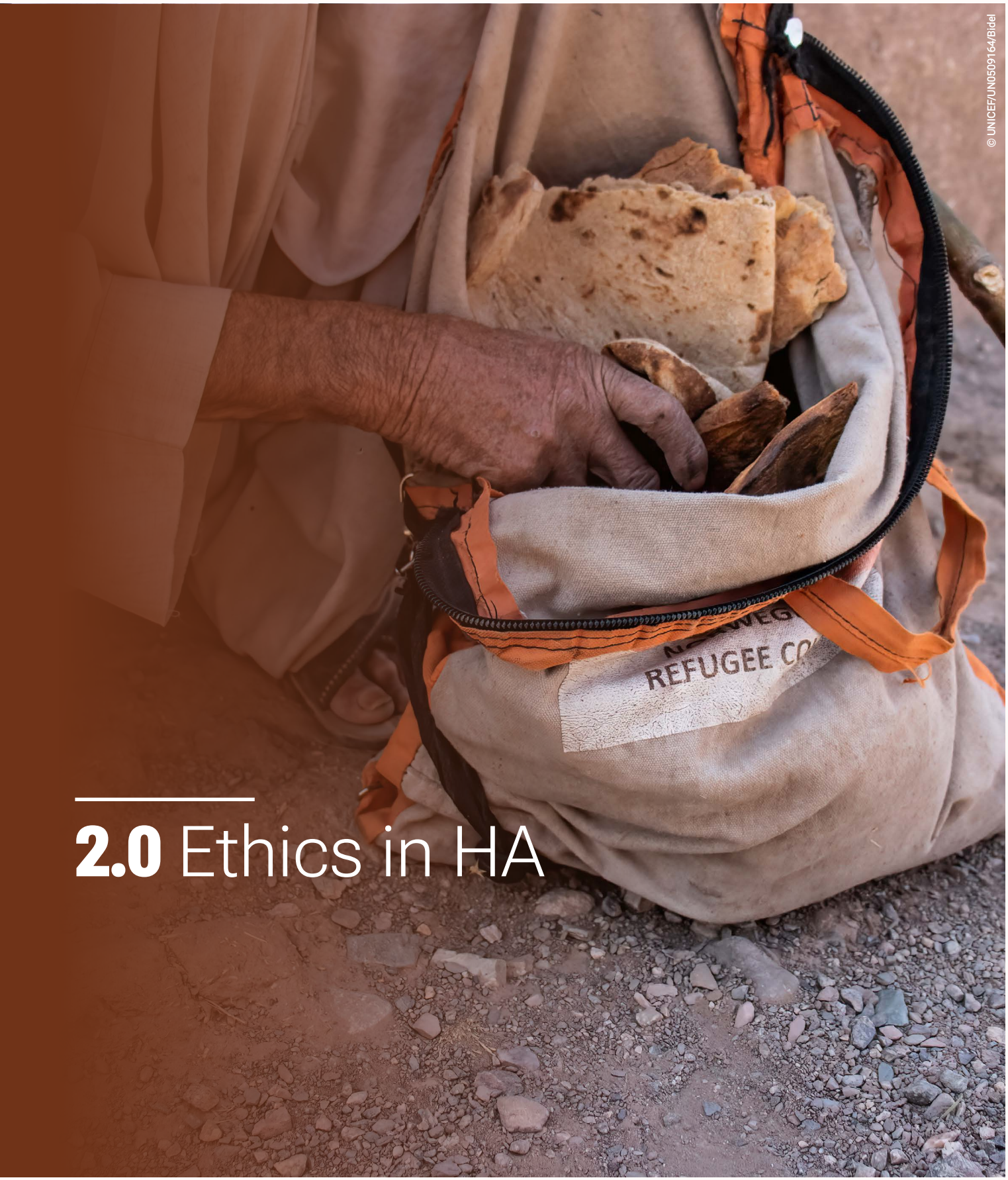
It is important to understand how and who is currently implementing social sciences approaches in HA. During humanitarian responses, mainly at the onset of a crisis and during the first two weeks of the response, social scientists might be part of response organizations and they are deployed with response teams. Their work focuses primarily on operational data collection and analysis. The findings of this review show that the people responsible for collecting operational social data are not often social scientists, but CE, health promotion, or other humanitarian (clusters) experts.

Further into the response, other actors can be present in field HA, like researchers from academic institutions, think tanks or private institutes. These positions can be geographically distant from the emergency setting or be present in the field just for the data collection period. These contrasting ways of producing knowledge have different objectives for such work, with implications in terms of researchers' independence, linked to their affiliation and consequent access to affected communities and time available to carry out the data collection, research and analysis.

Academic research often operates within long timeframes and, arguably, with a solid political independence. Social scientists in academia undertake long periods to design, prepare and implement field work. Academic research projects often undergo extended rounds of ethical boards' reviews. These prolonged work-frames, in turn, give researchers the possibility to analyse the evolution of relevant issues over longer periods, as well as to adopt a historical perspective (i.e., reflect on lessons-learnt by reviewing past crises) and a comparative one (i.e., draw comparisons between different crises, contexts, responses).

Field implementation of social sciences approaches during responses, however, needs to be prompt, functional and operational. It should be directly linked to the mandate of the organization or agency the person is working with. The possibility to implement this work is sometimes constrained by funding as it is not a standardised activity integrated in emergency operations. Humanitarian responses require timely evaluation and management, where adaptive programming and rapid life-saving actions are required, making traditional ethics reviews impractical. (Schopper et al, 2009). For instance, informed consent for primary data-collection, or permission for secondary data use, are challenging to request in rapidly evolving emergency settings where information is urgently needed to inform response strategies. Another matter that requires examination is de-identification. On the one hand, de-identification of research participants (a common practice in social sciences) could be problematic in circumstances where it is necessary to keep data to identify missing or deceased people who are wanted by their family. It is also possible to use de-identification data when used as a secondary data-source. These unique challenges, along with inadequate oversight and regulatory efforts by host countries and international mechanisms, make ethics considerations a crucial but difficult task in HA (Mfutso-Bengo et al, 2008).

In the perspective of developing guidance for the application of SS4CE in HA, there is a fundamental gap to be bridged between standard research times and ethical protocols in academic settings and in humanitarian settings. The current project takes these financial, logistical and time-related challenges into account, to envision an effective, and operational, framework for substantive integration of social sciences in HA, particularly in the CE.



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2.0 Ethics in HA

2.0.1. **Normative sources and core ethical obligations in HA**

Humanitarian action is an area where significant ethical challenges are constant, complex, and often entail life-or-death choices. For this reason, humanitarian aid is regulated by multiple sources of obligations (see Lidén, 2020), ranging from international humanitarian law and human rights to the core humanitarian principles (humanity, neutrality, impartiality, and independence) (Pictet 1979), as well as agency- or sector-specific regulations (e.g., Prieur, 2012; Sheather et al., 2016; PHAP, 2017). These norms and principles are diverse in their level of detail and specificity, their adequateness to current humanitarian contexts and their accountability to at risk and affected peoples. Together, they constitute the main normative framework for HA, and they outline the core ethical principles regulating humanitarian efforts.

HA and social sciences: principled vs. pragmatic ethical approaches

The dialectic between ethics and effectiveness has been a fundamental challenge in defining ethical principles and guidelines in HA. Due to the complex nature of the operating conditions, where resources and time are limited and humanitarians operate under multiple stressors, it can be difficult to apply ethical principles (Hunt, 2008). Principled, versus pragmatic approaches have characterised the history of contributions on ethics in HA (for emblematic instances, see: Slim, 2015; Terry, 2015; Fassin, 2007). From prioritising humanitarian aid functions, such as delivering food assistance to an internally displaced people (IDP) camp, knowing that militias gather there to benefit from that aid, to stopping humanitarian assistance on moral and uncompromising principles (Magone et al eds, 2011). These two dimensions need to be reconciled; for a humanitarian intervention to be 'good, balance needs to be struck between the dimensions of ethics and effectiveness, since the effectiveness of operations depends on upholding ethical principles as much as some ethical principles may be unrealistic when they do not take effectiveness and pragmatism into account.

When thinking about the application of SS4CE in HA, the challenge in the dialectic between ethics and effectiveness is also present. If we consider social sciences being part of relief operations with assessments and research activities (surveys, interviews in which data collection will be held, etc), the respective ethical frameworks are not perfectly aligned. Part of the complexity and specificity of the work within this project originates in the attempt to;

i. identify where SS ethics and HA ethics align and what common ethical principles can be found, and specifically regarding current community engagement actions
ii. address the long process and significant budgets of academic research ethical reviews and possible adaptations to the speed and objectives of HA in some of the stages of the HPC
iii. whether the humanitarian system can in turn internalize the importance of accurate ethical reviews for the application of SS4CE, to both steer and legitimize its own efforts.

2.0.2. **HA ethical conundrum: power dynamics, language and data use**

Humanitarian action, by its nature of moral endeavour (Slim, 2015), has been long considered a testing ground for applied ethics. While multiple case studies from humanitarian interventions have been analysed ***per se,*** or have served as examples of ethical scenarios, HA has also been the object of fierce ontological and occasional critics. Scholars have notably questioned its purpose and means, as an emanation of Global North powers ("the left arm of the Empire"; Agier and Fernbach, 2011), as well as the underlying politics of life whereby humanitarians, particularly expats, deserve higher protection and privileges on the field by virtue of their engagement (Fassin, 2007). Indeed, ethical issues are not only highly challenging but also constantly evolving in HA, where the configuration of technologies, of crises, and thus of aid, changes significantly over time.

Humanitarian action, like all fields of work, has its own technical language, this includes the specific ways in which at risk and affected people are named and classified. Individuals are considered as 'victims' 'survivors' of violence, 'beneficiaries' or 'recipients' of aid (Slim, 2015), also as 'suspect', 'probable' or 'confirmed' cases when deciding to treat, collect data (Hunt, 2008) or feeding affected populations' data to AI algorithms

(Pizzi et al., 2020). For all types of decisions, individuals working in HA need to receive adequate 'ethical literacy' and to be oriented and held accountable to up-to-date *norms to make informed ethical choices* when doing their work at all levels.

Ethical principles steering these choices have been in place for years (for a summary of the 17 main ethical principles in HA today, see Slim, 2013). However, these principles require further modernization and contextualization, particularly looking at how to turn abstracted information into measurable observations, improving equity between all parties and devising scenario-based approaches. This would facilitate better self-determination among individuals, including but not limited to how to decline HA interventions in the face of new challenges in their specific situation, as well as how to exercise their right to access and use collected data, or even how to opt-out of the dataset at any time in the future.

There are numerous humanitarian organizations and established working groups building on data responsibility and data sharing codes. OCHA, the Inter-Agency Standing Committee, the ICRC, among others have all produced principles and guidelines for data responsibility and protection. The Data Responsibility Working Group (DRWG) works "to coordinate, support, and monitor collective action on data responsibility", bringing together stakeholders in the humanitarian system, including United Nations structures, as well as international and nongovernmental organisations. 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.

2.0.3. **Power Asymmetries**

A fundamental ethical question, both in academic research and in the HA fields, is how to avoid, or minimise, asymmetries. The literature refers to power asymmetries in global Health, in disaster and emergency management research and in humanitarian aid (Abimbola et al, 2021; Jason and Knox, 2022; Aloudat and Kahn, July 2021).

The Coronavirus Disease 2019 (COVID-19) pandemic, the Black Lives Matter movement and ongoing calls to decolonise HA have all created space for uncomfortable but important conversations that reveal serious asymmetries of power and privilege that permeate all aspects of HA. For some scholars and practitioners, the current form of humanitarian aid, perpetuates "its historical entanglements with colonialism and politics, its engagement with power, and its complicity in extending disasters" (Aloudat and Khan, July 2021). Some of the recommendations provided by Aloudat and Khan include:

- Move away from a Eurocentric, white saviour view of humanitarian interventions.
- Move away from the pretence of 'apolitical' humanitarianism. The attempt of depoliticizing humanitarianism is, in and of itself, a political position that accepts the status quo and delegitimizes any challenge to the current world order.
- Link humanitarian aid with other social justice issues such as the action against racism, coloniality, and the effects of the climate crisis, etc.
- Move away from making decisions on behalf of people to following their lead and providing technical assistance and resources when they need it.
- Prioritise "indigenous humanitarian actors in all countries who shoulder the burden of assistance. The international community should be working for them, not vice versa." (ibid).

In this mapping review some questions appear as potential sources of asymmetries that will be highlighted in the future guideline in the following dimensions:

i. **Origins of knowledge systems and contextualization of global goods**: Most documents and binding guidance originate and have their content developed in the Global North based on Eurocentric conceptualizations and understandings of ethics; there were no local documents found or referenced that express local knowledge systems and understandings of ethics and compliance mechanisms and reparation processes. These are important to address asymmetries in North-South power dynamics. Accordingly, a 'global good' should be inclusive of conceptualizations and processes that originated in different cultural systems than the European. There is a need to (re)define or expand global standards that are inclusive of contextualization processes to ensure local cultural knowledge and practices are systematically incorporated.

ii. (ii) **Donors´ requirements, humanitarian goals and the reality of at risk and affected communities.** Despite the narrative on HA being based and driven by needs alone, criticism points at the fact that donors (and aid agencies alike) are the ones defining the agenda. There are calls for

a reform in the humanitarian system to re-orient processes away from the priorities of aid agencies and donors towards the needs of affected populations. The humanitarian system underwent a series of reforms.[2] Among them, a package of comprehensive commitments between donors and aid agencies to efficiency, effectiveness and transparency, known as the Grand Bargain, was launched during the Humanitarian Summit in 2016. Participants committed to improve humanitarian financing by increasing direct support to local and national responders, reducing earmarking, harmonising duplicative processes, and including people receiving aid in making decisions which affect their lives.

iii. (iii) **Academic research ethics and objectives.** Like with HA, there is an extensive body of literature that analyses the need to decolonize research methodologies and social sciences (Tihuwai Smith, 1999; Reiter, 2021). Authors refer to the process of reflectivity needed in the research process. Reflectivity regarding researchers' subjectivity, their perspectivity shaped by social origin and biographical life path, or their possible asymmetrical power relations with investigated actors. There is no straight and easy answer to the big questions of "for whom" and "for what purpose" social sciences produce "what kind of" knowledge and "how." The question at stake is how coexisting yet diverse conceptions of academic research and knowledge production can be reflexively considered and related to each other from an epistemological, ethico-normative, and ontological point of view. (Severine et al., 2021). Thambinathan and Kinsella (2021) draw on theories of decolonization and exemplars from the literature to propose four practices that can be used by qualitative researchers: (i) exercising critical reflexivity, (ii) reciprocity and respect for self-determination, (iii) embracing 'other(ed)' ways of knowing, and (iv) embodying a transformative praxis. They consider an ethical and moral imperative to embrace decolonizing approaches when working with populations oppressed by colonial legacies.

2 https://www.thenewhumanitarian.org/analysis/2016/02/11/humanitarian-reform-what-s-and-table

2.1 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. For instance, the resolution adopted by the Global Privacy Assembly (2020) brings together practically every nation's authority charged with data protection. Other organisations that have addressed this are the regimented documentation specified in the UN Global Pulse (2020), and the International Committee of the Red Cross' (ICRC) data protection manual (Kuner & Marelli, 2020). The Office for the Coordination of Humanitarian Affairs (OCHA), as part of their mandate as leading coordinating UN agency for HA, manages the Center for Humanitarian Data. The focus of their work is to increase the responsible use and impact of data in the humanitarian sector. They work on resources addressing data responsibility, like the Data Responsibility guidelines (October 2021), and a series or 'tip sheets' providing humanitarian partners guidance on different aspects of data collection, processing, analysis, storage and use (i.e., Understanding Data Ecosystems, July 2022).

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, involving the safety and protection of people. Regulations applying specifically to humanitarian crises are crucial to establishing consent and placing limits on processing personal data outside crisis contexts.

2.1.1. Data Ethics and Ethics of Data

Undoubtedly, we are facing a big challenge to ensure that the data collected will safely transit among innumerable affected communities and institutions that use different platforms and database aggregators (such as OCHA, ICRC, European Union, World Bank). The reliance on data triangulations from different sources supported by algorithms, and inferences about groups and populations has become increasingly frequent in many sectors, including the humanitarian field. Data is a valuable strategic asset in supporting evidence for action when used in a responsible and equitable manner. However, poor data-collection practices, unauthorised use or modification, accidental loss, improper disclosure, and/or sharing of information as well as decontextualized use of primary or secondary data can jeopardise humanitarian aims and place individuals, groups, or entire communities at risk.

At the onset of humanitarian responses, much of data, if not all, is collected to identify the people who are affected by the crisis and require support from humanitarian organizations. The data from these actions are stored in databases that may, or may not, be used in future activities. It is believed that from the point of view of preparedness for a HA, the data collected can be useful for strategic planning. But datasets may also be required by donors for their own purposes: all these aspects must be thought about when discussing ethics in data sharing, considering who will access this data, for how long, in what way and most of all, the intentions behind the usage of data are inceptive when consent of participants is first sought.

Differently, the data collected by social scientists, within academia, has a priori purpose; the data brings sense and meaning to the research, allowing testing of hypothesis, and conclusions to be achieved. Before social scientists can apply their research in the field, with vulnerable groups, their methodology will be scrutinised by an ethics committee (ERB, IRB, etc.). Each person invited to participate in research must be informed of the intent of the research, its objectives, the management of the data that will be collected and given the opportunity to withdraw themselves or their data at any time during the research. Only after signing a consent form for the specific collection and use of data by the researchers, the compilation begins.

In the case of HA, it is important to note that data is collected from numerous methods and sources, such as key informant interviews, from documentation found in the scenario, from records made by other actors in the field, and from governmental databases available to the public.

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HA and research in the social sciences follow different paths with how they observe data ethics, it is important to discuss how these paths can meet, coexist, and complement each other, always for the benefit of people. For example, data collection protocols can be formalized and standardized for preparedness and emergency phases in the HPC. Such protocols can include both procedures and techniques used in academia and humanitarian ethics principles and priorities framed in the need to standardize contextualization and the inclusion of locally relevant knowledge and practices.

Aspects related to the integrity of the data collected, based on previously planned protocols and standardizations, will often be more rigorous when they are a product of academic research. Nevertheless, it is important to acknowledge the work being conducted by OCHA and other organisations to develop guidelines for data responsibility in HA, through the safe, ethical and effective management of personal and non- personal data for operational response. Research in the social sciences considers the possibility to use the data collected for long periods, which can be used for monitoring and/or subsidising new research, for example. The databases from research in the social sciences have great potential for reliability and validity and may come to form part of other databases through ethically authorised sharing and proper protection of people´s sensitive data.

Challenges to data usefulness in HA are addressed in data storage platforms through techniques such as, data harmonisation. Such procedures often have as a consequence bias that produce distortions capable of mischaracterizing the original data. It is a known risk that harmonisation of data from an original source can result in the quality of information being downgraded.

2.1.2. **Responsibly leveraging data protection and confidentiality in HA**

Due to the growth and availability of data through innovations in technology (algorithms, artificial intelligence, learning machines, data mining and big data), their use has become increasingly frequent in many sectors, including in HA. Data used in a responsible and equitable manner, can be a valuable strategic asset as evidence for action, to provide visibility for recognition of individual, group and community rights and interests, and to generate scientific knowledge. Datasets are also a great asset for communities, as they are informative and can contribute to decision making at local level, if communities are involved in the process of data collection and aware about the potential of their use.

Statistical analysis, and big data can include personal data such as ethnicity or disabilities, as well as at risk and affected communities' social and cultural context information. Although this allows for more precise, representative, and informed deductions to be made, it is important to consider that this sort of data is sensitive data. Sensitive data can also facilitate the identification of groups or communities putting them at risk. Some of the risks associated with the use of data in an irresponsible, misguided, or even intentional manner, can perpetuate inequalities, racism and ableism and can be used to harm a specific group or community. When used in a responsible and equitable manner, data can be a strategic asset to develop scientific knowledge and evidence for action, as well as providing visibility and recognition of groups, their rights and interests.

There should be an intention and a structured plan behind the use and collection of statistical data, and other forms of data, in order to prevent exposing sensitive data, ensuring that only necessary data will be collected. The declaration of interests and objectives of the procedures, as well as the request for consent from participant at risk and affected communities should be taken before work starts.

2.1.3. **Data sharing and data responsibility in HA**

Data sharing and 'data responsibility' in HA are closely intertwined and have constituted the focus of multiple analyses and recommendations for the humanitarian system. Data sharing and mechanisms to regulate it have deeper historical roots in public health emergencies (PHEs). Institutions and platforms for data sharing in response to health emergencies *long* predate the 21st century, with interventions from the League of Nations in the early 20th century, the World Health Organization from 1948 and its creation of surveillance networks from the 1960s. The Belmont Report, written by the US National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, published in 1976, identifies basic ethical principles and guidelines that address ethical issues arising from the conduct of research with human subjects. According to the literature, despite having been developed before technology had

opened the door for the generation of millions of gigabytes of data, posing unprecedented challenges to human-subject ethics, the core principles of the report are broad enough to cover these aspects (Paxton, 2020). On the HA side, the Center for Humanitarian Data from OCHA published the Data Responsibility guidelines (OCHA, 2021) which also address how OCHA should implement the IASC Operational Guidance on Data Responsibility in Humanitarian Action (IASC 2021).

Data sharing regulations in PHEs and in HA share important commonalities, including:

Privileges and immunity of key humanitarian actors.
Certain structures and actors seem to have important privileges and immunities concerning data sharing. For instance, certain international organisations enjoy immunity from jurisdiction which means they have immunity from legal process and the protection of their in-country presence, documents and data from being accessed. These organisations also have testimonial immunity which means the organisation and their staff are exempt from testifying or providing evidence in legal proceedings in order to protect their neutrality and independence in a given crisis. This raises specific concerns and uncertainty about the complexity involved in the 'data' concept and its coverage, and concerns about data quality.

Lack of clarity around the place of social sciences' data in data sharing.
In PHE, from the mid-1960s, anthropological and social sciences data was side-lined in favour of data that emerged from the objective questionnaires that could generate pooled information - i.e., population/clusters data, resorting to informal data sharing, that is, without data sharing agreements or other formal arrangements. Such sharing in PHEs tends to be guided by long-standing collaborations, and at times, historical and linguistic relations between the countries of teams engaged in data sharing. The sources of information (for example, interviews with key actors as a religious community leader) can be reduced or chosen at convenience, without a deep reflection about the implications these biases may have in the data collection and production of information, and the (theoretical) conclusions or (political) strategies that result thereof.

Objective of research and data collection to be mutually beneficial.
People affected by a humanitarian emergency may have an interest in the information generated being useful regarding solving the problems that affect them, such as preparing to face another crisis. It is not evident how this use of the data collected is obligated. While the concept of 'ownership' and collective action has become a critical construct in community engagement for HA, a fundamental principle should begin with equity in research and data collection objectives. There has been mounting efforts and evidence that reinforce the linkage between ownership of communities and the accountability and quality of humanitarian aid.

Data sharing of sensitive data, at all moments beyond the crisis.
Concerns about what is sensitive data and how to protect people from harm by identification, without losing data quality and usefulness. Data sharing improves in emergency contexts, but declines once they pass, as research interest dries up once a project on health emergencies ends; the challenge is how to preserve that data for new research or as a baseline/learning for other emergencies. Another critical dimension sharing is data security. Despite data security, especially that could potentially affect or harm people or groups negatively, as fundamental, it is often underfunded and therefore dangerously overlooked.

Needs, risks, and grey zones associated with social sciences for CE data sharing

The needs for, and risks associated with, data sharing are both of critical importance. Social data collection in HA contributes to more rapid and effective responses. Sharing such data is justified on diverse grounds, from facilitating more effective operations, to ensuring accountability to communities, organisations and donors, documenting HA, as well as ensuring compliance with humanitarian principles. The risks associated with social sciences for CE data sharing, however, are several.

In principle, there appears to be a consensus that organisations only collect and use the data that they need; Fast (2022) has noted, "data management at the field level is driven by multiple demands and actors, often resulting in a mismatch between these tenets." Our interviews with professionals and field workers, and the analysis of a selective literature yielded the following risks, detailed below.

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

Sets of sensitive data are generally those that would increase "likelihood and severity of potential harm that may materialise as a result of its exposure in a particular context"[3] and can include personal and non-personal data. OCHA HDX has developed a data sensitivity classification, identifying different types of data used in humanitarian responses, the levels of sensitivity of those data types, and appropriate sharing channels. Other organisations have developed their own classification systems for sensitive data. The fundamental issue to address is how to balance the need to respond to a humanitarian emergency and save lives, and the simultaneous need to protect privacy.

Nevertheless, OCHA has warned that "setting out a definitive list of Sensitive Data categories in Humanitarian Action is not meaningful [so that] appropriate safeguards (e.g., technical and organisational security measures) have to be considered on a case-by-case basis." (Kuner & Marelli, 2020: 15). Hence, a 'one size fits all' classification is harmful because each humanitarian setting has its specific actors, organisations, affected publics, problems and priorities, and thus what may not be sensitive data in one humanitarian context might as well be in another. This *adaptive, contextual approach to sensitive data is important to safeguard at risk and affected people*. Humanitarian crises take place in high-risk settings with vulnerable communities, who may not be able to give fully informed consent to each step. Flexibility around sensitive data can potentially produce inconsistencies across datasets and HA practices, and Berens and colleagues (2022) argue that the absence of technical and ethical standards could result in harm to these peoples. It is crucial that data sharing procedures have categorised 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. This issue is extremely complex and needs special attention, and with the advancements in technology the 'world is shrinking' and data becomes available anywhere on the globe.

Big data and the use of machine learning to collect data from social media can be useful in providing insight into human movement and location data but can also pose risks to individuals and social groups. Although users post on such platforms as Twitter, Instagram, TikTok, or messaging groups such as WhatsApp, Telegram and Signal, *ethicists have noted that users do not provide consent for the re-use of their posts for other purposes, such as the collection of data for HA*. Although such data may be useful in crisis contexts, it can also raise significant ethical problems when used, for instance, by private corporations, which harvest such data for their own benefit.

2.1.4. Data retention storage

In its handbook on data protection, the ICRC provides the following guidance on retention: "Data should be retained for a defined period (for three months, a year, etc.) for each category of data or documents. When it is not possible to determine at the time of collection how long data should be kept, an initial retention period should be set. Following the initial retention period, an assessment should be made as to whether the data should be deleted, or whether the data are still necessary to fulfil the purpose for which they were initially collected and further processed and, therefore, the initial retention period should be renewed for a limited period of time." (Kuner & Marelli, 2020:43)

This guidance, however, effectively begs the question of how long a database is useful and relevant. This gap is particularly problematic for social sciences data, which must attend to the specific social and historical contexts, actors, and broader changes associated with humanitarian crises and responses. Additionally, 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. In this situation, the problem is how to ensure this happens. The problem is further compounded by our participants' observations that in conflict areas, data storage and protection can be highly limited, frequently underfunded, and require a high level of data and computational literacy. Social sciences data that contain personal or sensitive information needs anonymization or pseudonymization to be shared, but such de-identification can prove time-consuming and complex in large or complex databases. In addition, secure storage of data does not offer absolute protection, above all when third parties participate in these processes or when a humanitarian institution hires an enterprise or NGO to do this work. Datasets can be, and are, breached by malicious actors, putting people at risk Since humanitarian organizations can be the only entities that can save records in humanitarian emergencies, data retention is of fundamental importance and thus should be flexible depending

3 Centre for humdata. (2022, November 11). *Glossary.* Available at: https://centre.humdata.org/glossary/#

on the situation and the potential use to identify sought individuals, as long as it is retained just to fulfil the purpose to which data was collected (Kuner & Marelli, 2020).

Data sharing and Secondary use of Data

Data sharing can take place through formal and informal channels, and thus can potentially result in increased risks for those involved in the crisis. In addition to these specific channels, OCHA has developed a formal platform for data sharing (Humanitarian Data Exchange, or HDX), with over 19,000 datasets, from nearly 1,800 sources, as of July 2022. The HDX website offers data grids detailing available data categories for specific countries. Its site also contains descriptions of databases that include qualitative and quantitative social sciences data for CE (e.g., Community Engagement Central Sulawesi Working Group Response; American Red Cross). That said, 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, as Westphal & Meier have observed (see figure below).

In addition, multiple reports have outlined difficulties navigating donor requests for data sharing, caught between the ethical problems of sharing sensitive data and a perceived obligation to share with funders. In this regard, OCHA states that donors "should only request the information required to meet the specific purpose for which it is being requested and should indicate a timeline for destruction of the data" (see OCHA Note #7: responsible data sharing with donors, p. 4). In addition, most interviewees emphasised the significant ethical and legal constraints involved in sharing data with donors, governments or enterprises contracted for certain works. For example, banks for cash-transfer programs that retain data of bank accounts and use it for other purposes beyond HA (Kuner & Marelli, 2020).

There are, however, important *barriers to data sharing*. The Grand Bargain Transparency Workstream[4] conducted field research with HA stakeholders in Bangladesh and Iraq, and found the following reasons:

- a lack of confidence among local and national nongovernmental organizations in both the quality of data collection and data itself,
- concerns about how data could be used by third parties
- the lack of capacity to share data on platforms and the cost of those platforms and statistical programs,
- the lack of data sharing agreements,
- data sensitivity,
- the perception that large institutions (UN agencies, international NGOs) are better and the owners of primary data

The concern raised in the previous section about the duration of database usefulness and relevance is closely linked to another – the secondary use of data. Data sharing implies that data collected for one purpose may be used for another. In public health emergencies, ethical review boards oversee the secondary use of clinical, biomedical and social sciences' data, insisting on informed consent for future uses and clear indications about what data will be stored and for how long. In HA 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.

2.1.5. **Data ownership**

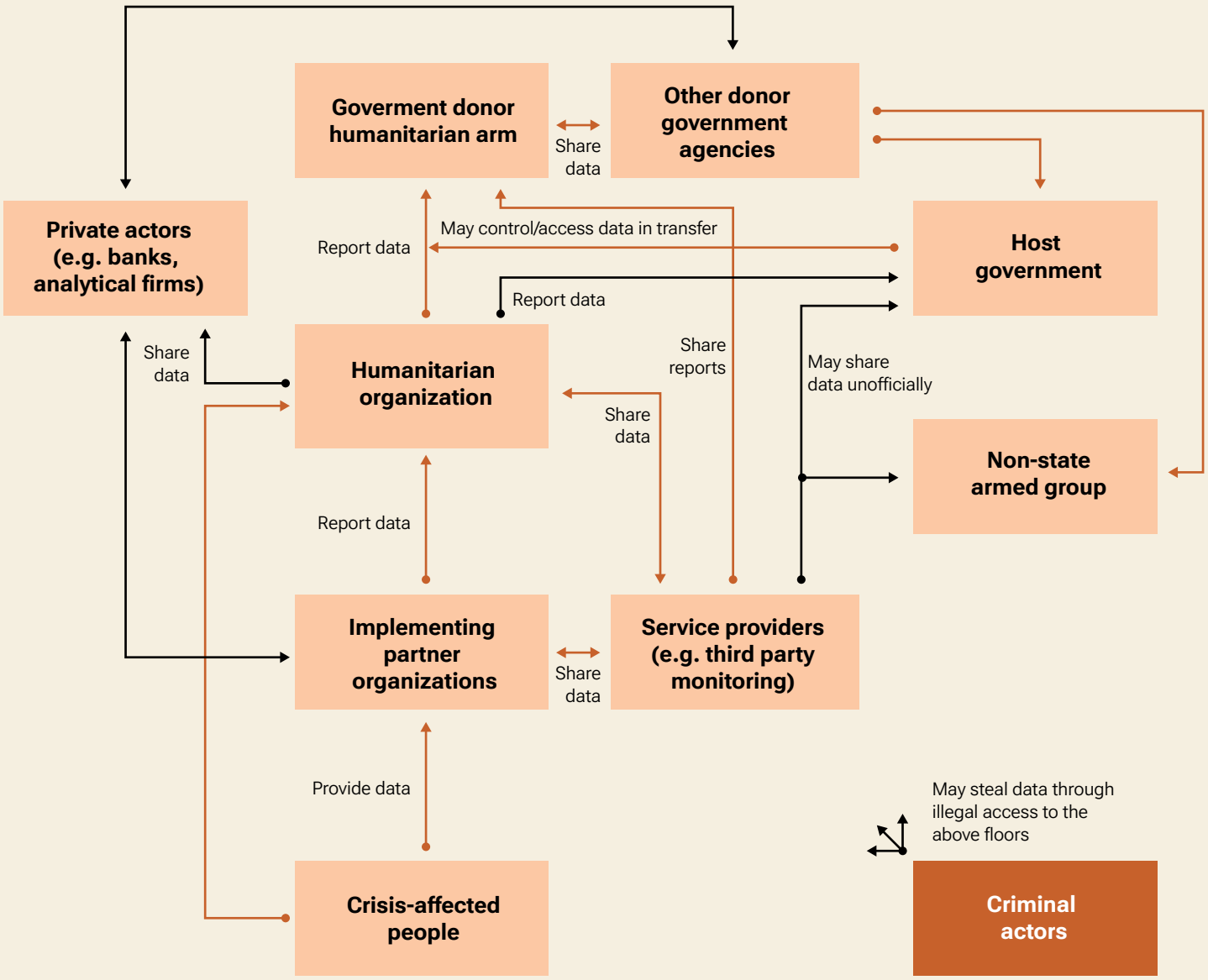
The question of *who owns data* is a central one cutting across nearly all debates around data management. It speaks to concerns of accountability to local populations that are the focus of HA. There are multiple initiatives to promote CE, access to information, and accountability in HA. The CDAC network[5], for instance, brings together local, regional, and global actors. At the same time, it appears that there may be a lack of clarity over data ownership, specifically related to the people who provided the data. How personal data is used, stored, shared, and re-used is particularly unclear in the case of displacement of such people. De-identification of ownership of data can be problematic when it is necessary to identify missing or deceased people, as occurs during wars, migration, and political conflicts.

4 https://www.icvanetwork.org/uploads/2022/04/The-Grand-Bargain-Explained-An-ICVA-Briefing-Paper.pdf

5 https://www.cdacnetwork.org/

FIGURE 1.

Data Flows in Humanitarian Systems and Research Scope



Source:
Figure from F. Westphal & C. Meier, 2020. Research on the specific risks or constraints associated with data sharing with donors for reporting purposes in humanitarian operations, Synthesis report. GPPi.

Risks related to this data flow are **covered** in research

Risks related to this data flow are **not covered** in research

3.0 Main considerations for ethics and data sharing for SS4CE in HA

3.1. Lack of 'fit for purpose' social data in humanitarian programming

When a crisis strikes, there is a critical need for CE and baseline data on local community's behaviours, knowledge, and practices, to be better positioned to inform responses and to include key actors on the ground. These baseline data are not always available and robust, as comprehensive, response-oriented data collection rarely takes place in the preparedness phase. The lack of fit-for-purpose accessible datasets often leads to multiple types of data and data sources being neglected during emergencies. There seems to be a missing link between social sciences, its frameworks and methods and humanitarian responses technical aspects. Often, social data being collected in relation to humanitarian programming is not connected to humanitarian programming needs. At the same time, it is not a given that social scientists performing these tasks are knowledgeable about the humanitarian system or technical priorities. It is important to understand that humanitarian programming will entail the encounter of different knowledge systems and priorities in crises contexts. Collecting relevant information that serves both communities and humanitarian priorities is a way to ensure its use. Some of the information needed to engage with key local actors to plan and implement effective and efficient responses often exists, but it is so fragmented, poorly managed and inaccessible to decision makers that it is practically unusable.

3.2. Harmonization of ethics mechanisms to measure effectiveness

This mapping exercise highlighted a lack of standardized or centralized ethics mechanisms for social data collection, sharing, retention and use processes with specific consideration to distinctions by different phases of humanitarian programming. Any efforts to set up standardised procedures should also consider the diversity of actors engaged in coordination and implementation of HA and the specificity of their mandates. Until now, these diverse actors have mainly relied on their own ad-hoc ethical approaches in collecting, managing, and using data in view of their different operational needs and overall purposes, which as detailed through the analysis pose considerable ethical tensions with the overall aims of HA and its overall objectives and principles. The need to harmonise applicable definitions, functions, and responsibilities throughout all stages of data management, from collection, processing, and storage, to preservation, access, and sharing in and beyond, operational contexts need to be developed among key actors. The implications on local accountability mechanisms need to be prioritised, with required investments in capacities and resources that could integrate social sciences for meaningful community engagement during HA. The credibility of these measures needs to further prioritise strengthening of compliance mechanisms and performance metrics at all levels of the humanitarian system and its operations.

3.3. Adaptation and contextualization in different humanitarian crises

Another aspect to be considered is the different nature of crises, as well as regional and country contexts. The type of crisis – epidemic outbreak, conflict (protracted), or natural hazard (disaster) – as well as the way it plays out in different geographical, cultural, legal, political, and social contexts bears specific challenges and implications. These elements should be addressed within an ethical framework that is implementable, useful and operational in humanitarian programming attaining a level of standardised approach to contextualization.

3.4. Principles, logistical and time-related challenges of ethical regulations in HA

A significant challenge to be addressed in terms of defining ethical mechanisms relates to conditions in which field application of social sciences takes place during humanitarian interventions. ERBs (Ethics Review Boards) are regulated by standards structures and protocols linked to academic institutions and biomedical research. Most often, these standards are incompatible with the principles, practices, timeliness of humanitarian interventions and the diversity of settings where crises occur. Another important dimension is establishing engagement with national processes, e.g., the participation of local ERBs in the process of approvals, and

how aware implicated communities are of this process and the intended outcomes. For instance, in the context of humanitarian emergencies, data collection should respond to the vital interest of individuals at risk (Kuner & Marinelli, 2020), contrary to the principles of conducting social research where the generation of knowledge is the main reason.

3.5. 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 limited in scope. None of the literature reviewed referred specifically to ethics around the implementation of SS4CE in HA at the different stages of the HPC. To some extent, ethical standards for social sciences are also derived from existing regulatory standards for biomedical research. Commonalities are mainly to be found in the sensitivity and personal nature of the collected data, both qualitative (e.g., a person's opinion on their country's government or linkages with certain community groups) and quantitative ones (e.g., a person's medical record or income or national origin).

Feedback from interviewees also asserted that an overall mapping of the different typologies of data collected in humanitarian operational contexts should precede such considerations (i.e., Schopper et al 2009). Social science data is used for different purposes; the main ones being operational and advocacy related - all these applications produce different types of data.

Qualitative methods typical of social sciences' research are robust, rigorous and provide highly precious data for engaging communities in humanitarian processes, and can contribute to ensuring that asymmetries in power dynamics are identified and acted upon. Despite these important contributions, the validity, richness, and usefulness of these methods, and the qualitative data collected, is not systematically recognized, in HA. The use of mixed research methods is necessary in secondary analysis from a programming perspective, as quantitative analysis needs to be adequately matched with qualitative insights to enable a more holistic understanding of the intervention and why it is or isn't manifesting the expected outcomes.

3.6. Creating a HA ERB

As explained earlier, the issue of ethical approval for the application of social sciences in HA was identified as one of the factors that needs to be addressed to ensure its operationality. Different organisations explained the way in which they apply for ethical approval mainly for data collection, either with their internal ERBs (e.g., academic institutions, WHO, NGOs, etc.), or following donor's processes (e.g., European Commission, Wellcome Trust). Academic ERBs were recognized as often slow, very costly and at times inadequate even for the much less significant time constraints of academic research and especially for humanitarian programming.

One of the interviewees shared the ICRC experience of setting up a specific ERB for the organisation in 2021. The social sciences team at ICRC found a gap when applying their work in the organisation's programmes that needed to be addressed. They had the need to set up an evaluation body that could operate safeguarding respect to humanitarian principles and meeting HA's operational criteria, and at the same time, ensuring research is ethically acceptable, checking investigators' potential biases, and evaluating compliance with regulations and laws designed to protect human subjects.

Building on the above, as well as deliberations among the technical working group put forward, an interesting and noteworthy proposal for the creation of a global Humanitarian Ethical Review Board (HERB). The objective of this global body would be to specifically work on ethical aspects and more significantly compliance mechanisms related to the ethical application of social sciences for community engagement in HA. This board, like the ICRC ERB, could establish mechanisms for the ethics review of operational data collection exercises during responses and research proposals addressing both HA and research ethics priorities, as well as track actions and decisions informed by these types of data.

The idea is that this global HERB will liaise with all existing relevant ERBs at country level, playing a bridging role and providing specific capacity on the application of social sciences that could lead to strengthening community engagement in HA. The HERB should further play an oversight role to ensure linkages with local ERBs that lead local processes of approval as well as the creation and implementation of locally relevant compliance mechanisms.

Discussions took place as to the composition, roles, responsibilities and the functioning mechanisms of this proposed HERB mechanism. This body, acting at global level, could be composed of members from different ERBs (country level ERBs, academia, organisations, etc.) from all regions of the world. The HERB should be connected to the IASC cluster system and relevant task forces.

The rationale behind the establishing of a global HERB mechanism that could connect with national level ERBs is also rooted in the recognition that western-based ERBs are not inclusive of alternative conceptualizations of ethics and compliance mechanisms. To function effectively, principles for an HERB need to be carefully adapted and co-designed with local communities and/or their CSOs - to avoid the imposition of global North concepts and processes. This could be a step in the decolonization of HA agenda, contributing to power sharing that transforms the sector into a more equitable one.

Critical limitations with this proposed global HERB were also discussed by multiple members of the technical working group. These limitations and/or concerns included the logistical, financial and time-related challenges related to the creation, support and maintenance of such a body which would be very resource intensive to set up.

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Conclusions

The intention of this mapping report was to examine the constructs and dimensions of data ethics and data sharing specific to the social sciences (academic), the humanitarian systems, and the application of ethics through social sciences specifically to contribute to meaningful community engagement in humanitarian programming. Through the processes and methodology of the mapping, identifying the tensions, commonalities as well as criticisms and gaps were explored. A member of TWG1 stated; "ethics is ethics wherever ethics are being applied." This statement is completely true. While reinforcing the significance of ethics, this statement delineates the importance of contextualization ensuring "fit for purpose" and "operational" ethics application driven by purpose, intents and objectives that are acknowledged and shared among all stakeholders, especially people and communities.

This exercise shed light on the fact that understandings, rules, regulations and ethical standards for both social sciences, the implementation of community engagement and implementation dynamics in HA, are based on western and Eurocentric perspectives and values that carry the legacy of colonisation, perpetuating unequal power dynamics with the Global South, where the majority of HA takes place.

One important conclusion is that the ethics guidelines that will be developed should address these very important aspects in practical terms. A prospective SS4CE in HA ethical framework should not take the shape of a norms checklist but should be structured as a tool to help the crafting process of implementation at the different stages of the HPC, with a series of principles to steer deliberation, enforcing the need to contextualise and trigger reflectivity processes about the role of the practitioner/researcher and local communities in each particular humanitarian crisis to arrive to an understanding of what is ethical, and what it is not, according to the context.

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

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