

Ethical primary research by humanitarian actors

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As humanitarian agencies increasingly follow the example of academia in establishing ethics review committees, one such agency reflects on the benefits and drawbacks.

In the late 1970s and early 1980s, Western research bodies and governments started establishing internal ethics review committees and these have now become the main way academic institutions address ethical concerns. In the case of non-governmental organisations (NGOs), despite conducting primary data collection as part of needs assessments, monitoring and evaluation, many of them formerly did not see research as being core to their mission. There was also an assumption that humanitarian guiding principles such as humanity, neutrality and impartiality were sufficient as a broad ethical framework for research activities.

However, as research becomes more complex, professionalised and increasingly integral to the activities of humanitarian actors both in the field and in advocacy, many NGOs are now setting up systems and processes to guide their research, following to some extent the routes taken by academia. Donors are also influencing this trend as they increasingly require those they fund to meet formal ethical requirements.

In October 2018, Save the Children UK (SCUK)¹ launched its own internal Research and Evaluations Policy, which includes provisions on research ethics and established an independent ethics review committee made up of external experts. The policy requires any primary research which SCUK is involved in to be reviewed by the committee. Shortly after its launch, we were asked by colleagues to lead on two pieces of primary research. This research involved collecting qualitative data in Nigeria and in the Democratic Republic of Congo from children affected by conflict and their caregivers as part of Save the Children's work to protect children in conflict. As part of this we worked with colleagues to produce two desk reviews to understand how to tailor

data collection to fill identified gaps; it soon became clear to us that some aspects of the planned research were already known about, thanks to studies by other actors.

Is primary data research necessary?

'Bad' research is not just research that lacks sufficient rigour; it also encompasses research that collects primary data to answer questions for which information is already available. Humanitarian actors are increasingly asked to be aware of potential 'assessment fatigue' and where possible to minimise primary data collection by increasing data sharing with other agencies and/or undertaking joint needs assessments. Any ethical consideration must start with a review of secondary sources in order to ensure primary data is only collected when absolutely necessary. With regard to data utilisation, however, poor knowledge management and high turnover of humanitarian personnel mean awareness of the data is poor, and this limits potential use. And in humanitarian crises, where contexts evolve continuously, and especially in protracted crises, aid organisations also face the challenge of understanding how long existing data remain relevant. As donors expect data to underpin proposals for new programmes, the question of maximising data use while ensuring data relevance is an important point for consideration, and one that cannot be addressed simply by an ethics review.

We hope that work under the Grand Bargain² will facilitate humanitarian research that is more ethical by encouraging efforts to seek published literature on the topic and better data sharing, knowledge management and intersectoral analysis. In addition, we recommend embedding secondary reviews as a requirement in ethical research procedures and considerations.

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www.fmreview.org/ethics

The application process

For our research on children in conflict, after checking for secondary sources we then prepared the application form for the ethics review committee. The form incorporates an analysis of potential risks for participants and mitigating factors, matters that may arise among participants and possible channels for referral, and the informed consent process. While on paper much of what was covered is standard practice in our work, in the face of competing priorities there is always a temptation to leave the planning for these aspects until the last minute. In humanitarian contexts the urgent need for evidence often takes precedence over the need for well-planned tools and data collection methods, meaning that aspects such as informed consent, anonymisation, data retention and enumerators' training can become afterthoughts. We therefore found that the requirement to put all these considerations in writing in advance provided a valuable check to ensure that SCUK-supported research meets minimum ethical requirements.

However, in some instances it felt burdensome to have to articulate to external reviewers some information that would have been clear to another SC colleague: for instance, we had to describe the steps we would take to ensure confidentiality but many of these steps are standard SCUK procedures, such as password-protecting access to any computer. For humanitarian contexts it is essential that these application processes are simple, concise and come with standard and transparent guidelines to ensure that staff view the process as a useful step in the research process rather than an administrative burden.

Usefulness of a review committee

Through the ethics review committee, two external experts evaluated the research

design and proposed improvements.

This was useful in highlighting areas we had not thought of, and was all the more useful when the experts provided practical recommendations. Inevitably, though, their relative lack of knowledge of SCUK's ways of working and resources meant that they sometimes missed potential improvements or ways to fill gaps – or made suggestions that were not feasible given, for example, the country context in which the research was to be conducted. We personally feel that there are advantages in having external reviewers but they should not replace internal reviewers. Having an expert with humanitarian experience and knowledge of the organisation's ways of working and

of the country in question is critical to ensuring flexible, quality research.

While our experience is, in many ways, unique to SCUK, we urge humanitarian actors to find meaningful and practical ways to ensure they follow ethical procedures and practice in order to protect research participants and support the people whom the research is seeking to serve.³

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1. The articles uses the acronym SC to describe aspects that pertain to the whole Save the Children movement (of 28 member organisations), and SCUK to refer specifically to Save the Children UK. Save the Children US (SCUS) has had a review policy and system since 2016. The SCUK and SCUS policies and procedures share similarities but are distinct and work in different ways; at the time of writing, we are exploring aligning or merging the two.

2. www.agendaforhumanity.org/initiatives/3861

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Bakassi IDP camp, Maiduguri, Nigeria.

UNHCR/Rahima Gambo