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Ethics and research in humanitarian settings

Magali Bouchon et Christian Laval • Médecins du Monde – France

Looking back on the seventh Scientific Day organised by Doctors of the World – France, the two authors discuss the ethical issues involved in research carried out in humanitarian contexts. From Niger to Nigeria to France, they point out the need to take better account of the views of the populations involved, explain the procedures and report the results.

In the humanitarian and other social fields, people and populations have long been considered mere objects of study and, as a result, little informed of the aims and methods of the research involving them. This lack of involvement has fostered misunderstanding between populations and research teams. It may have also led to distrust and even public rejection of teams. Ever since the Nuremberg Trials of 1945–1946, however, ethical considerations as applied to medical research have been formalised through an international normative framework.

At Doctors of the World – France *(Médecins du Monde* – MdM in French), research is designed to help build knowledge that will improve effective access to healthcare, generate expertise to support advocacy and support people in their drive for social change. At a time when it increasingly calls upon scientific research, our profoundly changing humanitarian response is itself increasingly confronted with many ethical dilemmas. Should we be involved in research that proposes therapeutic trials with populations in dire poverty in return for remuneration? How can someone not lose their freedom of consent if, in exchange for taking part, they receive free healthcare? The ethical principles of protecting participants in research in humanitarian settings fall within the social responsibility remit of non-governmental organisations (NGOs). This is why MdM's Board, having called for the adoption of a Research Ethics Charter, decided to devote its seventh Scientific Day for Humanitarian and Inclusive Health (*Journée scientifique de la santé humanitaire et solidaire* in French), held in December 2021, to the subject of ethics and research in humanitarian fields.[1] At this event, we wanted to share the topical issues that we encounter in humanitarian research and that are never fully resolved by committees, charters or legislation.

The ethical aspect of human vulnerability: three examples from the field

Ethical issues raise questions about our attitudes and our research, especially as the situations of vulnerability in which the populations for which we intervene find themselves (traumatic history and social precariousness) require us to take all the necessary protective measures. At our Scientific Day, we decided to place our ethical issues in the specific context of humanitarian practices, avoiding an overarching set of ethical principles that would not take our intervention contexts into account. The methods for recruiting participants and obtaining consent and for managing the benefits and risks for

[1] The event's programme and filmed talks are available on the Doctors of the World website (in French): https://www.medecinsdumonde.org/fr/actualites/evenements/08-12-2021/journee-scientifique-de-la-sante-humanitaire-et-solidaire-2021

participants were some of the many issues discussed and which we shall illustrate using three examples from the field: in Nigeria, in Niger and in France.

In North-East Nigeria, the armed attacks of the last ten years have forced more than two million people into internal displacement, living in camps or with host communities. Many factors increase the vulnerability of people fleeing conflict or disaster: disruption of community protection mechanisms, separation of families, increased socio-economic fragility, overpopulation, crowding and so forth. As a result, displaced people are exposed to unequal power situations. All these factors were the motivation for the NGO Population Council's research[2] into barriers to access to services for survivors of sexual violence in Nigeria's Borno state. The question was soon raised, however, about the risk of the harm that this research might generate because of the increased vulnerability of the people concerned who, in addition, depend on the host populations, government services and associations. These multiple dependencies and allegiances may question the voluntary nature of the consent to take part in a research project. In this context, how can research not become another negative experience?

Our second example is from the Covid-19 pandemic, which is known to have shed light on neglected marginalised populations and highlighted existing social inequalities. In the absence of early treatment and care and a health equity policy, the situation proved devastating for the homeless, the inadequately housed and the most vulnerable, fragile and isolated people. How can equal access to care, medical confidentiality and free and informed consent for the most precarious people be guaranteed? How can we screen if, once a positive result has been obtained, we cannot isolate, or simply give the results to, people who, by definition, are in a precarious housing situation? These questions arose at each preparatory stage of a research project aimed at assessing mortality and seroprevalence[3] in people living on the streets of Marseille, France.

Mortality due to the pandemic appeared to be higher among the poorest and foreign-born. Pre-existing factors of social inequality – living in group emergency shelters or having reduced access to healthcare – increased seroprevalence, and the Covid-19-related lockdown accentuated the already major social difficulties and precariousness of many people in Marseille.

With the target populations in great distress, conducting the survey proved difficult. Screening was offered at a mobile PCR test station. To deliver the results, discreet and confidential places had to be identified so as to limit the risk of stigmatisation and, more broadly, to implement a comprehensive approach involving help to find a hostel, help to find a facility where those who tested positive could isolate, the distribution of food and sanitary products, etc.

Lastly, an example of a randomised controlled clinical trial[4] in Niger shows that research is never just a scientific endeavour. In this case, the aim was to evaluate the efficacy and safety of a new vaccine, Rotasiil, against severe forms of rotavirus-induced diarrhoea in children under two years of age. Here, efforts to produce reliable data clashed with the social conditions of their collection. In this trial, which was conducted in a rural environment, women and their children received free healthcare in exchange. To ensure the roll-out of the trial, the agents periodically took biological samples. In practical terms, for the women and children in this region, where access to care is difficult and the health system largely deficient, taking part in a clinical trial was equivalent to saving their child's life.

[2] https://www.popcouncil.org

[3] The cohort consisted of 1,400 people living on the streets, in emergency shelters or in squats or slums.

[4] A randomised controlled clinical trial allows "the results from a group of patients treated with the drug to be tested to be compared with those from a group of control patients, the 'control' group, with both groups being monitored simultaneously". See Patrice Jaillon, « L'essai clinique contrôlé randomisé », *Académie nationale de médecine*, 3 avril 2007, https://www.academie-medecine.fr/lessai-clinique-controle-randomise (editor's note and translation).

Some rural areas were excluded, however, because they were not deemed cost effective for the trial in terms of demographic weakness and the additional logistical means required to mobilise participants. This led to inequalities, not only in terms of access to care, but also in terms of access to resources for part of the community. Furthermore, the document used to obtain consent was written in French whilst the translation into the local language was too "standardised". It therefore proved difficult to explain to some women that their child could either have a vaccine that may make them better or have a placebo, just as it proved difficult to explain the adverse effects of the vaccine. Finally, in practice, the idea of individual consent clashed with a strong patriarchal culture in which only the man of the family, including the grandfather in the absence of the father, could allow the woman to take part.

As we can see, the implementation of these three research projects routinely raised ethical issues for the research teams but also for actors in the field. They highlight the full range of reflexivity and sensitivity needed when engaging in this type of project. They require suitable methodologies to be developed.

The lessons learnt in a humanitarian context

Obtaining consent from individuals is the first ethical dilemma faced by research teams in contexts where the requirement to respect the principle of autonomy of the individuals approached and their right to have information is never taken for granted. In poor countries or among vulnerable populations, participants in a trial are often unaware of the risks and benefits of actually taking part and do not know whether the aid is conditional on taking part or whether taking part helps them to obtain more aid: this is referred to as "therapeutic misunderstanding". Compensation (allowance, transport expenses, food, medicine, etc.) requires some thought about choice – or rather the absence of real choice. These "advantages" of being included in the participants' register raise questions about the actual process that leads to consent when consent itself has become an ethical standard that claims to be normative and universal.

Many ethics committees insist on written consent. In reality, signing a form does not guarantee that the person signing it has been informed or that they have understood what they have signed. Such a procedure does not necessarily mean anything to people who are not educated or who live in a society where, when an important decision is to be made, it is customary to address the issue orally in front of a witness. In other words, the administration of consent cannot apply everywhere in the same way.

Biomedical research, however, often travels with theoretical tool kits which claim to be universal but are hardly ever compatible with the local reality and structural inequality of the countries in which the research is conducted. The direct benefits of that research for participants are all the more questionable in that the number of studies in humanitarian contexts is increasing to such an extent that there may be constant collection of data, and it is not uncommon for some people to take part in several studies simultaneously. The risk, verified in the field, is that people become disillusioned when their living conditions are not improved in return or simply when the results of the research are not shared and made accessible in a timely manner to people and those in their immediate circle. For these populations, the issue of accountability arises at all stages and, with it, those of confidentiality and the need to make the results intelligible and useful. To question ethics is also to question how to communicate and present results to the most important people concerned: the participants.

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From individual to collective: how can ethical considerations and research work together within NGOs?

The relationship between ethics and humanitarian aid is complex and unsettling. Nurturing ethical concerns is difficult in practice, given the extent to which ethics challenges our values, our very existence, our mandate. In severe crises, urgency can lead to "suspensions" of ethical vigilance. During the Ebola crisis, many of the dead were not identified before they were buried. To what extent can we forgo doing the right thing? When is the red line of the key "do no harm" principle crossed?

Humanitarian aid embodies strong values of inventiveness and transformation. Our strength lies in being as in tune with the context as possible. What we have learnt in practice – and what MdM's seventh Scientific Day admirably confirmed – is that ethics in the field must be given precedence over top-down ethics: the challenge for an NGO is to build a shared ethical culture at both individual and collective level.

To put ethics into practice is "to take care of oneself and others" – a process which is built into a given space and a given time. We must constantly ask ourselves about the nature and context of the interaction and how we negotiate with an individual with a view to maintaining some kind of recognition of what makes them unique. The ethics of *care*, as defined by MdM in its ethics charter, allows the issue of the value of interacting with a person but also with the community of which that person is part, to be properly addressed.

To nurture ethics in the field, it is essential to share a sense of ethical culture: having principles is useful, but the actors in the field must be able to defend them. Work is needed to formulate the dilemma, and the sharing of experiences is essential in this respect. Humanitarian aid workers, wherever they operate, should have access to a forum where they know that they will be listened to, so as to help them analyse their situation and thus enable them to act within it. Words are also based on previous experiences and stories and how issues were resolved or not. Stakeholders should have access, at least in part, to such a body of experience. These stories are powerful enough to understand the importance of recognising oneself in others.

Translated from the French by Derek Scoins

Biographies

Magali Bouchon • Magali Bouchon is a social anthropologist. Following her research on the treatment paths of patients with severe and chronic diseases in Mali and then on adapting health education materials to local concepts, knowledge and practices in Senegal, she joined Doctors of the World (MdM) in 2007. She contributes to the "Access to care and socio-cultural determinants" project which aims to improve the effectiveness and quality of humanitarian action by taking the socio-cultural context into account. Today, as manager of the research and learning processes unit, she leads the design, implementation, analysis and value-enhancement activities of knowledge-production approaches such as mixed research, evaluation-capitalisation and monitoring tools. In association with MdM's advocacy, she helps to promote the organisation's visibility and expertise on priority themes.

Christian Laval • Christian Laval has a doctorate in sociology and his research interests lie at the crossroads of extreme precariousness and mental health. He is a research fellow at the Centre Max Weber Lyon 2 and at the Centre for Research on Social Inequalities, Discrimination and Alternative Citizenship Practices (CREMIS) in Montreal. Secretary-General of Doctors of the World – France (MdM) between 2013 and 2019, he is currently a member of France's National Advisory Commission on Human Rights (*Commission nationale consultative des droits de l'Homme* in French) on behalf of MdM.

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