



---

# Ethical standards rapid literature review

## Final Report

---

Prepared for //  
Louise Davis, DFID

Date //30 May 2019

By// Dr Lisa Thorley  
[lisa@iodparc.com](mailto:lisa@iodparc.com), Emma  
Henrion [emma@iodparc.com](mailto:emma@iodparc.com)

Leslie Groves (Quality  
Assurance)  
[lesliegroves@gmail.com](mailto:lesliegroves@gmail.com)

IOD PARC is the trading name of International  
Organisation Development Ltd//

Omega Court  
362 Cemetery Road  
Sheffield  
S11 8FT  
United Kingdom

Tel: +44 (0) 114 267 3620  
[www.iodparc.com](http://www.iodparc.com)

# Contents

Acknowledgements	iii
Acronyms	iv
Introduction	- 1 -
Purpose and scope of review	- 1 -
Background	- 1 -
Methodology and limitations	- 2 -
<i>Limitations and possible biases</i>	- 2 -
Findings	- 3 -
Framing issues	- 3 -
Findings on approaches to ethical principles	- 6 -
Beneficence and non-maleficence	- 6 -
Respect, human rights, equity	- 10 -
Safeguarding, sexual exploitation and abuse	- 11 -
Security of identity and security of data	- 13 -
Informed consent	- 14 -
Humanitarian and conflict settings	- 18 -
Honesty, competence, integrity and accountability	- 20 -
Conclusions	- 22 -
Annex 1: Bibliography	- 23 -



# Acknowledgements

This review has benefited from the expert inputs and suggestions for materials from the DFID Ethics Reference Group, chaired by Alastair Ager. Louise Davis, DFID, provided thoughtful and constructive suggestions as the review progressed, as well as efficient coordination within DFID. Stephen Porter, Oxfam America provided invaluable thinking and contributed recent materials on safeguarding and ethical approaches to evaluation, as well as sharing examples of draft safeguarding training materials safeguarding developed by Oxfam America. We were privileged to have an excellent and thought-provoking conversation with Michael O'Donnell and Prisca Benelli, Save the Children UK, on the practical difficulties of implementing ethical approaches in the field, and on ethics in relation to monitoring. Dugan Fraser, CLEAR, University of the Witwatersrand, kindly commented on a draft of the accompanying ethics guidance and FAQ, and provided valuable critical insights and challenges. To the extent possible in a literature review which was required to be short and rapid, we have endeavoured to address the contributions of all. Any errors or omissions are, of course, the responsibility of the review team.

# Acronyms

ACFID	Australian Council for International Development
AES	American Evaluation Society
CIOMS	The Council for International Organizations of Medical Sciences
CBO	Community Based Organisation
CRC	The Convention on the Rights of the Child
DFID	Department for International Development
DPIA	Data Privacy Impact Assessment
ELRHA	Research for Health in Humanitarian Crises
ESRC	Economic and Social Research Council
EQUALS	Evaluation, Quality Assurance and Learning Service
GDPR	General Data Protection Regulation
GSR	(UK) Government Social Research
INGO	International Non-Governmental Organisation
IRB	Institutional Review Board
MSF	Médecins sans Frontières
OECD	Organization for Economic Cooperation and Development
ONS	Office of National Statistics
RCT	Randomised Control Trial
REC	Research Ethics Committee
SSA	Sub Saharan Africa
SEAH	Sexual exploitation, abuse and harassment
SEA	Sexual exploitation and abuse
UKDCR	UK Collaborative on Development Research
UNEG	United Nations Evaluation Group
UNICEF	United Nations Children's Fund
WFP	World Food Programme

# Introduction

## Purpose and scope of review

This rapid review of ethics related to research, evaluation and monitoring has been commissioned by the Department for International Development (DFID). Its purpose is to inform an associated set of guidance for DFID staff working on research, evaluation and monitoring, provide wider reference within DFID and to identify good practice. The review draws on both published and unpublished research and practice of donors, research funders and professional associations that relate to ethical standards, principles and guidance in research, evaluation and monitoring. It considers research and evaluation ethics in relation to development and humanitarian work, both of which are important areas for DFID, and makes specific reference to safeguarding issues.

For this review and the linked guidance, DFID proposed five draft standards to consider as follows:

- Sound and culturally appropriate design, application and conduct of research, monitoring and evaluation with relevant dissemination and use of findings.
- Participation based on informed consent and sensitivity to the cultural context of the research. Participants should be informed that they may withdraw consent at any time.
- Enabling participation in ways that consider the rights of all to participate equitably and with dignity.
- Consider the anticipated benefits and possible adverse effects on participants and identify mitigating strategies for the latter.
- Identity (whether of person or organisation) should be protected and information kept secure.

## Background

DFID has been consistently committed to improving practice in relation to research and evaluation ethics. DFID's ten ethics principles were an important first step in attempting to systematise consideration of ethics across different sectors and different types of research and evaluation (DFID, 2011). These principles were reviewed in 2015 and changes recommended (Groves, 2016). This review provided a light touch analysis of ethics principles, guidance and practice currently used by DFID, other donors/ commissioners, and providers of evaluation and research to DFID. The 2016 review's overall recommendation was that *"DFID has a responsibility to provide clearly articulated ethics principles, to communicate these effectively to those with whom it works and then hold different parties to account for meeting them... within a context where the need to balance possibly conflicting ethical issues is understood as part of a process-oriented approach"*. There were also more specific findings and recommendations, which are relevant to the current review. There was an expressed intent from DFID to continue the work to develop revised ethics principles and guidance. There is therefore a body of relevant past experience, data and knowledge to draw on, which has been used to inform the current review and guidance.

## Methodology and limitations

### *Method*

A systematic review methodology was originally proposed for the literature review. However, in practice this was found not to be the most effective approach, and instead a snowballing approach was used. As a first step, the web and journal data bases were searched for documents and guidance using relevant search terms. This produced a core of literature. References were followed up and added. As well as searching by search term, there was purposive search by institution for relevant institutional guidance and codes of conduct for research and evaluation ethics. These institutions included multilaterals and bilaterals, research bodies, UK government, and national/regional evaluation societies. DFID also supplied documents and information related to DFID policy and practice. The review included both grey and academic sources, published and unpublished, peer reviewed and non-peer reviewed literature. The 2016 Groves review was also used as a source of information and analysis.

### *Limitations and possible biases*

- The review team would have liked to have drawn more from research funders and professional associations within the Global South. However, in the context of the Global South, research ethics committees are often not well established or absent (Cochrane, et al. 2018). There is a scarcity of scholarly resources relating to ethics in the development context (Chattopadhyay et al, 2017). Searches for ethics guidance by country and region found very few examples.
- In the context of the Global South, there are limited numbers of research funders as well as professional research associations, reflecting the power relations between the Global North and South. The review has therefore drawn in the main from literature produced by research funders and professional associations from the Global North.
- Evidence demonstrating the usage of ethical guidance was limited by the lack of evaluations assessing use of ethics and guidance. There is little data on the *use* of ethical guidance in evaluations, their efficacy and continued relevance and value.
- There is notably little literature on the ethical implementation of monitoring systems.
- There is a bias towards English language publications, as a result of the team’s decision to search only these. This will have resulted in some literature being excluded.

#### **Note on terminology:**

**Research/evaluation and researcher/evaluator** are used interchangeably below, except where specified. While there are differences in the use of findings from each, the majority of the issues below apply to both.

**Guidance** is used throughout the review to refer to institutions’ guidance on ethics, although in practice institutions use terminology that includes guidance, guidelines, principles, codes of conduct, codes of ethics, all of which cover similar issues.

# Findings

## Framing issues

### *Approaches to ethics in international development research and evaluation*

The “*notion of ‘ethics’ is a complex construct, imbued with particular values and beliefs that influence how we approach research*” (Graham, et al, 2010:134). As Bloom (2010) summarises, ‘*Ethics ... involves a set of principles of right conduct that is supposed to govern practitioners’ behaviours in clinical and social change situations*’. The Economic and Social Research Council (ESRC) guidance defines ethics in research as being, “*the moral principles guiding research, from its inception through to completion and publication of results and beyond*” (ESRC, 2019). Ethics are therefore founded in moral values and behaviours.

Moral principles are not universally shared. In applying ethical guidance, the researcher needs to find a balance between the guiding principles of the ethical guidance so that it is appropriate to the context and culture of the intervention (Laws, 2003). There is a school of thought that proposes that the notion of universal research ethics is not appropriate, and that instead we should consider situational ethics, since ethics are culturally and context specific (Ebrahim, 2010). In the context of many African societies, societies where DFID works, moral thought is based on the morals of a community, rather than morals of the individual, ‘*Individualistic ethics that focus on the welfare and interests of the individual is hardly regarded in African moral thought*’ (Gyekye, 2010:8).

In international development there is limited shared understanding of what is meant by “ethics” in evaluations and research. There is frequently ambiguity on the purpose and function of ethics. From a review of ethical guidance used by 20 different organisations working in social research, health and international development we found a wide variety in approaches to conceptualising ethics. Ethical guidelines do not consistently provide clear definitions of the ethical principles underpinning them. There are some notable exceptions to this rule where guidance clearly defines the framing ethical principles used (UNICEF 2015; ACFID, 2017). Many evaluation handbooks do not refer to ethics (Duggan & Bush, 2014). Institutional ethical guidance can therefore be unclear and open to interpretation, and often lacks a strong base in ethical principles.

There is a lack of clarity in the use of the term “*ethics in relation to the other necessary components of good research and evaluation*” (Groves, 2016). “Ethics” is often used to describe not just the ethical principles but also the guidance used to operationalise the principles. This can lead to confusion as to what ethics are, and what their purpose and function is. For instance, a number of institutional ethical guidance documents reviewed addressed technical approaches to methodology, commissioning process, funding, independence and conflicts of interest, without considering the ethical issues and choices underlying these (DFAT, 2017; Australian Evaluation Society 2018; CIDA, 2004). Research ethics are based on rules that look to codes of conduct, research governance frameworks and ethics review procedures (Banks, et al. 2013). as Madushani notes (2016: 26) “*research ethics is a codification of ethics of science in practice...it is based on general ethics of science, just as general ethics is based on commonsense morality.*”

A variety of ethical principles are used in the guidance of different institutions working in international development. Principles identified are often consistent with the key principles of research ethics of: **informed consent, confidentiality, do no harm and beneficence** (Gillion, 1994). The United Nations Evaluation Group (UNEG) propose that research ethics principles include: **utility, integrity, transparency, respect and accountability** (UNEG, 2008). UNICEF



identifies **respect, beneficence/non maleficence, justice** as key ethics principles (Berman et al 2016; UNICEF, 2015). An analysis of 20 institutional ethical guidance documents reviewed by Groves found that there were no values or standards which were shared by all, and there was a widely varied approach (Groves, 2016,). The ethical principles of respect, human rights and equality were most frequently included, followed by a commitment to confidentiality. Do no harm was included by only seven guidance documents. These findings were confirmed by our own review of 20 other, different guidance documents. There is, however, a strong stated commitment across the majority of the guidance documents to adopting a moral approach to research and evaluation. This approach often combines a commitment to ethical standards with personal and professional competence: *“All those engaged in designing, conducting and managing evaluation activities should aspire to conduct high quality work guided by professional standards and ethical and moral principles”* (UNEG, 2008).

### Key points from section

- Ethics are founded on moral values; these are not universal.
- In international development, there is limited clarity and shared understanding of what is meant by “ethics” in evaluations and research.
- There is wide variation in the “ethical” values and standards used, but a broad commitment by organisations working in international development to “ethical principles”, although these are often undefined.

### *Applying research and evaluation ethics in health and social sciences*

Health research is strongly based in established ethical procedures and standards, procedures and standards that reflect good international practice. Health research is framed by the Nuremberg code which states that experiments on humans are permissible only if: the results will benefit society; the subjects involved freely provide consent and can withdraw at any time; and no harm, loss of chance or discomfort to the subject will result from the investigation. Vulnerable subjects are entitled to additional protections. The Helsinki Declaration 1964 introduced consent by the legally authorized representative of research subjects who are incapable of giving informed consent to enable children to be research participants. This has since been extended to people with impaired cognitive ability to enable their participation.

Health sector research draws on rigorous ethical requirements and scrutiny, stemming from the Nuremberg code. Research proposals which affect human subjects are required to undergo scrutiny through Institutional Review Boards (IRBs) or Research Ethics Committees (RECs) for approval, introducing external scrutiny and a clear set of ethical principles and standards to meet, so that abuses are prevented (Katz, 2006). This is especially important in poverty settings where abuses in health research have been known to happen (Kruger, et al 2014), with HIV medical trials at the forefront of this debate (Molyneux and Geissler, 2008). However, health evaluations are not necessarily subject to the same level of scrutiny, since evaluations are generally exempt from the IRB process.

The primary reason given for generally exempting evaluations from IRB scrutiny and approval is that evaluations are not seen as developing or contributing to generalisable knowledge, but undertaken to improve a specific practice or programme (NHS Health Research Agency, 2017). There is a debate in the research literature as to whether evaluations and research require different ethical standards (Bloom, 2010; Raifman, et al, 2018). The rationale given for using different standards is that evaluations address accountability and the purpose of evaluations is not to generate knowledge but to

assess the success of projects. The argument posed against this is that some evaluations are conducted for the purpose of learning, and do generate new knowledge and evidence.

Evaluations, particularly large ones, are subject to quality assurance processes which may assist with adherence to ethical principles. For instance, DFID's independent quality assurance service provides for a limited review of ethics considerations in the terms of reference, inception, mid-term and final evaluation reports. The World Food Programme (WFP) has a similar independent quality assurance process. Minimum financial thresholds for the evaluation contract are used by both organisations, so that only larger/more expensive evaluations are assessed. There does not appear to be any monitoring or quality assurance of research or evaluations from an ethics perspective for those that fall below the financial threshold (Groves, 2016). This potentially exposes participants and evaluators involved in smaller evaluations to risk of ethical principles being breached.

Although the Nuremberg Code and the Helsinki declaration were adopted by social science researchers to guide ethics within the social sciences (Barnes, 1979), health research principles are not always considered as completely appropriate to social science research. Social science research proposals must also be submitted to IRBs/RECs for approval, but there are sometimes tensions between the methodology and the REC standards framed on practice suited to clinical trials. Though the use of IRBs and RECs is of importance in relation to seeking ethical clearance, the usefulness of IRBs and RECs has limitations, and constraints. Ethical clearance processes are known to be very bureaucratic and sometimes over protective so that research is delayed and/or prevented (Powell, et al 2012).

The credibility of guidance provided by IRBs/RECs based in the Global North for evaluations and research taking place in the Global South may be challenged by researchers and institutions in the Global South. Ethics committees in the Global North may have insufficient knowledge of local context, and prioritise the requirements of their own institutions rather than focusing on the interests of the research participants. As Zwanikken and Oosterhoff (2011) suggest, reviews are often merely a 'ticking' the relevant boxes exercise. There is a further complication in that Global South ethical clearance processes, as noted by Kruger et al (2014) are primarily modelled on RECs in the Global North. *"Defaulting to western bioethical frameworks assures that the proposed research is in line with high-income country codes of research ethics, compliance with such frameworks alone may not be adequate for ensuring the safety, dignity and autonomy of participants in low- and middle-income countries"* (Nayfeh and Charron, 2018: 1).

## Findings on approaches to ethical principles

The findings below first discuss the ethical principles of beneficence/non-maleficence in the context of undertaking evaluations and research with research/evaluation participants. This is followed by more detailed sections on: respect, human rights and equity; safeguarding; security of identity and data; informed consent; humanitarian settings, and then discusses the ethical principles of honesty, competence and integrity for researchers and evaluators. These areas were selected to reflect and encompass the main ethical issues that are commonly identified as key to address in the wider ethics literature and guidance. Some case studies are presented which often illustrates challenges; however research ethics apply to all situations, the everyday as well as extreme situations or issues.

## Beneficence and non-maleficence

### *Beneficence*

Beneficence is identified as a key ethical principle for research and evaluation by several organisations. UNICEF (2015) defines beneficence as *“The principle of beneficence refers to the requirement that actions within evidence generating activities promote the well-being of individuals, communities or society as a whole. The principle of beneficence requires the identification of clear benefits likely to arise from evidence and to reconsider proceeding if these cannot be articulated.”* Other guidance raises questions asking how the research is important to the affected community, and what potential harms might arise if it is not undertaken (Government Social Research, 2011; ELRHA, 2015). However, guidance tends to focus on “do no harm” – rather than on *“broader ethical issues such as the common good [or] social justice”* (Groves, 2016).

The concept of beneficence in terms of benefits to society or communities is not consistently referenced in either the international development organisations’ ethical guidance reviewed or in UK government guidance (Government Social Research, 2011; DFID, 2011). Evaluation and research terms of reference and proposals rarely set out the benefits and utility to different stakeholders. Beneficiaries, as opposed to national or international stakeholders, are not often clearly defined in development programmes and evaluations. A review of institutional evaluation guidance for an International Non-Governmental Organisation (INGO) notes *“the ‘loud silence’ about beneficiaries whereas the place of ‘partners’ and donors is visibly secure.”* (Etta, 2018).

This imbalance of benefit to different stakeholders reflects the power imbalance that is often associated with international development research and evaluations. The programmes and evaluations are funded by donors, generally from the Global North, who have a different set of interests to those from the Global South. These tensions and conflicts are highlighted by Bhutta (2002), who presents examples of public health research undertaken in developing countries which conform to international health regulations and processes but fail to address issues of socioeconomic deprivation and equity, relevant to the community where the research was conducted. Bhutta makes the case for a more participatory research process, which engages national bodies as well as local communities in the research design. It is also noted, for instance by ACFID (2017), that in a development context, the research process itself should be viewed as an ‘intervention’, with its own impacts and consequences, and as such, should carry a commitment to support empowerment and participation and that including beneficiaries in the process can build local capacity

A more radical approach to reframing and shifting evaluation practices and ethics is proposed by Hopson (2018), who refers to the *“tension for evaluators to identify the key interests, interactions, variables, and stakeholders amidst dynamic and complex issues at program, policy, and project levels.”* .... and to recognise the *“personal and political nature of evaluation.... To affect the lives and*

*communities of those who are powerless.*” (Hopson 2018:4). Hopson’s argument makes a case for increased relevance through indigenisation of evaluations and increased collaboration and co-creation and equity. Researchers based in the Global South set out an approach for adapting western evaluation approaches in Africa to become more relevant and appropriate to African culture and ontology. Such changes are seen to increase the value of evaluations to communities and reduce power imbalances through providing a more relevant practice and methods (Chilisa, 2016).

**Two-way feedback and conversations**

The evaluation team had an initial set of in-country meetings with community members to gather information and to discuss/agree the draft research questions and tools. These informal, guided conversations with beneficiaries (and programme staff) used tools such as life history interviews identifying changes in individuals’ lives and drivers of those changes, to be able to understand the effects of the project on their current situation.

(Restless Development, in Groves, 2015).

Beneficence includes the concept of reciprocity and accountability. Communication and feedback with beneficiaries throughout the research cycle is seen as good practice by some, so that there is a more reciprocal and open relationship with communities (ACFID 2017; Groves, 2015; Save the Children UK, 2018b). Ensuring there is two-way feedback throughout is aligned with treating people with respect (see below), as well as contributing to a better-informed evaluation.

Dissemination is something that should occur throughout the course of the research cycle and be participatory in nature. As recommended by the ESRC (2019), evidence generated should be communicated to participants so that they can understand their contribution and potentially gain from the knowledge disseminated. Putting research findings in the public domain, enables the work to be open to scrutiny and debate. Findings need to be presented in a way that is accessible to all stakeholder audiences, including for example, donors, country governments and institutions, research participants. Language and format need to be considered for accessibility and relevance (ACFID; 2017; Save the Children UK, 2018b; ERIC, 2013).

**Using video to feedback**

A screening was held by the beneficiary participatory video team to share and discuss views with other beneficiaries and support transparency. Copies of the video were disseminated as were photo stories taken from the video.

(InsightShare for UN Women, in Groves 2015).

The responsibility for disseminating research and evaluation findings is often not clearly identified. More often than not, evaluations are commissioned primarily for the benefit of the project implementor or the donor. Neither time nor resources are set aside for an appropriate dissemination plan, with project beneficiaries most often not included in the dissemination work (Groves, 2016). Dissemination of findings to participants and beneficiaries is critical to ethical working: *“respondents are entitled to know what it is that you are saying about them!”* (Laws et al, 2003:242).

There is often a lack of engagement with research and evaluation participants once the work is complete. Reports are often not accessible to research participants, especially research participants who are classified as being poor and marginalised. External evaluators of development projects often ‘parachute in’, they are in the ‘field’ for a very short period of time and are employed for a specific job (Whitmore, et al, 2013). They are the gatekeepers to the data; however, they are seldom in the position to relay to the people who they have worked with the results of their evaluations. The words of one refugee illustrate this,

*“We are really fed up with people just coming and stealing our stories, taking our photos and we never get anything back, not even a copy of the report. Nothing ever changes.”*

(Pittaway and Bartolomei, 2003:36)

### *Non-maleficence*

Non-maleficence is taken as a central principle within health and social science research ethics. “Do no harm” has been more widely used as a term in the humanitarian field, but in practice has the same meaning. “*It refers to organisations’ responsibility to minimise the harm they may be doing inadvertently as a result of their organisational activities*” (Keeping Children Safe, 2014). Avoidance of harm often refers to harm to individuals and communities. Within DFID guidance it encompasses both social and environmental harm (DFID SmartGuide on Safeguarding, 2019.). Some of the institutional ethical guidance reviewed identifies do no harm/non-maleficence as a key principle (UNICEF 2015; Government Social Research, 2011, ACFID 2017; SRA 2003; UNEG 2008), although some refer only to *minimised* risk to participants (NHS Health Research Agency, 2017).

The issue of the balance between the potential benefits and negative impacts of evaluations and research is widely noted in the guidance, with a frequent, though not universal, requirement that the risks should at least be balanced by benefits. In some cases, researchers consider the extent of the potential utility and value of the research as a mitigating factor against the potential risk or discomfort (ERIC, 2013). Some guidance refers instead to acceptable levels of risk (WHO, 2017), without defining what is acceptable. Other literature introduces a higher bar, for instance researchers have a responsibility for protecting research participants from any physical, emotional or social harm that might result from the research (Ennew & Plateau, 2004; Laws & Mann, 2004). UNICEF guidance states that the research must stop or be adequately amended if it puts participants in danger (UNICEF, 2015).

Risks and benefits can appear more clear-cut in biomedical studies than social research. Research with children is illustrative. For example, in randomised controlled trials (RCTs) used to develop vaccines for children, some children may be exposed to risk, although there may be great benefit for the broader child population. However, while the potential for physical damage is less likely to apply in social research (Hill, 2005), it can also be intrusive and cause great distress to participants “*Harm’ is often invisible and elusive, complicated by different estimations, different viewpoints – researchers’, children’s or carers’ – and difference between short- and longer-term outcomes*” (Alderson & Morrow, 2011:23). As Spriggs (2007) suggests, identifying benefits and harms to children participating in research is not always straightforward. Benefits can be hard to define and assess, and causality difficult to determine with some benefits (and harms) not known until long after the research is complete.

There are researchers who argue that the principle of ‘do no harm’ is insufficient to ensure ethically sound research, and that even if there is no intention to cause harm, it can occur (Jacobsen & Landau, 2003). This suggests that when seeking informed consent, especially in a humanitarian crisis, the process is insufficient (Barnes, 1979), since although consent may be given, unintended harm could come to the research participants. As noted by Mezinska, et al (2016) the guidance for research ethics in disasters has a distinct lack of clarity about ethical concepts, such as risk, vulnerability or harm. The methods that are employed in research in humanitarian crisis need to be considered with some care (Leaning, 2001). For example, surveys or focus groups can unintentionally cause harm to those who participate in the research as their participation can lead to hostile attention being directed to them by others.



Research/evaluation methods and implementation may also introduce risks. Again, taking the case of research with children as an illustrative example, preventative measures are needed to safeguard children if research/evaluation activities are to take place in unfamiliar places and outside family care. Using participatory research methods, researchers need to consider whether these are appropriate for children and whether they put them at risk, for instance whether participation in the research may impact on children and young people’s everyday lives in terms of revealing information. Privacy needs to be protected when the research study is exploring issues with stigma attached such as issues related to HIV/AIDS or mental health (Clacherty & Donald, 2007; Hunleth, 2011; Nyambedha, 2008) or issues where participants may give information which provides a minority or dissident view. Anonymity needs to be explained to children who wish to use their own names without realising that this may put them at risk.

Beyond harm to participants, the concept of do no harm also requires consideration of potential harm to researchers themselves, particularly in terms of safety, potential trauma, culture shock and availability of emotional support. These are risks in conflict and humanitarian settings (Duggan & Bush, 2014) but are relevant to all evaluations.

#### Research with people living with HIV

It is known that HIV is amongst one of the most stigmatised health conditions globally, especially in Sub Saharan Africa (SSA). There is a risk of harm to the participants if they are publicly identified.

In many places in SSA, even in remote areas, there are likely to be informal or structured support groups for people who are living with HIV. Access to these groups could be gained confidentially with the help of health care professionals from local clinics. Alternatively, if risks are first considered and addressed, clinics or a local community based organisation could act as gate keeper to the research. Issues around confidentiality still need to be considered. Accessing people who are living with HIV needs to be done with caution. Employing a peer researcher could be another route to accessing people who are HIV positive.

### Key points from section

- Beneficence is not consistently referenced in the ethical guidance reviewed.
- The intended and unintended beneficiaries are often not clearly defined.
- Evaluations are funded by donors, generally from the Global North, who may have a different set of interests to stakeholders from the Global South; donors in general may have different interests to end beneficiaries.
- Beneficence includes the concept of reciprocity, including dissemination of evidence to beneficiaries.
- Do no harm is a central principle for evaluations and research, but is understood in different ways - is it absolute, or a harm relative to risk and benefits?
- Minimising risk requires definition of what level of risk is acceptable, to whom and when.
- “Do no harm” may not be sufficient to ensure ethically sound research, since even if there is no intention to cause harm, it can still occur.

## Respect, human rights, equity

Respect for human rights, equity and dignity is frequently referred to in guidance as a key principle for evaluators and researchers, as is a requirement to understand and respect different cultures. *“Evaluators honour the dignity, well-being, and self-worth of individuals and acknowledge the influence of culture within and across groups.”* (AES, 2018). Linked to this principle, guidance emphasises the importance of respecting individual autonomy and therefore giving weight to individuals’ opinions and experiences, and their capacity to make choices and exercise judgement. Respecting autonomy is nuanced by the fact that *“personal agency may be limited due to age, circumstance or personal capacities. In this context, respect for autonomy requires recognition of capabilities, power differentials and the degree of agency that an individual may have.”* (UNICEF, 2015). The WHO Code of Conduct for Responsible Research (WHO, 2017) elaborates this as... *“[take] into account the underlying inequalities and the diversity of persons and communities, and [to] strive for equity and justice in health research.”*

The majority of guidance – including DFID’s EQUALS framework – takes a strong approach to ensuring that research and evaluations are gender and equity sensitive. Developing a gender sensitive approach is seen as important for the principles of justice and do no harm, since it facilitates the participation of women in the evaluation. A gender-sensitive approach enables evaluators to ensure that there is a clear focus on women’s concerns and experiences, which may otherwise be missed (UN Women, 2015). The focus on gender can also be applied, suitably adapted, to other groups that experience disadvantage and exclusion, such as people with disabilities, older people and children. In addressing exclusion it is also important to consider the intersections of disadvantaged groups, for instance children with disabilities or older women. By involving different groups of participants in developing the research methodology, the researcher can identify approaches which are tailored to each group’s specific experiences. The concept of justice requires evaluators to consider how research samples are constructed ensure that different groups benefit, and to avoid injustice from social, racial, gender and other biases. Linked to respect for equity is the *“consideration of who benefits and who bears the burden of evidence generation”* (UNICEF, 2015).

*“All programs and projects need to take gender, culture, power, privilege and human rights into consideration”* (Etta, 2018).

As part of ensuring respect and dignity, *“Evaluations must be sensitive to the beliefs and customs of local social and cultural environments”* (UNEG, 2008). A similar requirement is included in different guidance documents for international development and humanitarian work, reflecting the fact that evaluators and researchers are likely to work in cultures different to their own. *“To design research that aligns with the ethical principles of respect, beneficence, research merit and integrity, and justice, requires a firm grounding in the relevant local cultural values, norms and the local historical and political context. For any given context, a first step is to identify key cultural values and customs and analyse how these impact on meaningful adherence and interpretation to ethical research principles”* (ACFID, 2017).

To support this sensitivity to local culture, research and evaluation designs should be informed by the involvement of participants and their communities and ensuring that this participation is continued through the research/evaluation cycle including dissemination. There is potential to extend this to community involvement or control over the research process itself and use the research as an opportunity for local capacity development (ERIC, 2013; Hopson, 2018).

## Key points from section

- Ensure respect for autonomy and inclusion of people with limited personal agency is supported in evaluations and research.
- Construct research samples to ensure that different groups benefit, and to avoid injustice from social, racial, gender and other biases.
- Ensure that evaluation design and findings address gender, culture, power, privilege and human rights.
- Ensure that evaluation methods and design are sensitive to the beliefs and customs of local social and cultural environments.

## Safeguarding, sexual exploitation and abuse

### *Safeguarding*

Safeguarding is key to the principle of non-maleficence, since it focuses explicitly preventing harm. In recent years safeguarding has received increased attention, following high-profile cases of sexual exploitation, and the increased focus on safeguarding within the UK on child and vulnerable adult safeguarding. In 2018, on the day of a Safeguarding Summit, the UK Collaborative on Development Research (UKDCR, 2018) made a collective statement of four UK government departments including DFID, and the Wellcome Trust, of their commitment to: higher standards in organisational culture, systems and practice to prevent and tackle all incidents of harm and abuse, and; to working collaboratively with their partners in the research and development community to strengthen safeguarding practices and compliance processes.

Safeguarding policies and processes for children generally address physical abuse, sexual abuse, sexual exploitation, neglect and negligent treatment, emotional abuse and commercial exploitation. However, safeguarding is also relevant to adults – particularly vulnerable or disabled adults, women and socially excluded groups. As well as focusing on protecting people (and for DFID and some other institutions, the environment) from unintended harm, safeguarding addresses preventing and responding to harm caused by sexual exploitation, abuse, harassment (SEAH). Underlying all safeguarding processes is an implicit or explicit recognition that safeguarding exists to mitigate unequal power relationships within societies which can allow those with more power to harm those with less (Berman et al 2016; UNICEF, 2015), including gender power inequality (Etta, 2018) .

Expert guidance on safeguarding observes that to be effective, safeguarding must be owned by the whole organisation and seen as everyone’s responsibility (DFID 2018 ; Keeping Children Safe 2014; Save the Children, 2018a). Keeping Children Safe guidance sets out a three element process, with all three elements seen as essential. Effective safeguarding starts with developing a clear policy, adopted by the governing body, which ensures that the organisation is aware of its safeguarding commitment and that all staff are accountable for it. To be effectively implemented, the policy needs to be supported by a systematic and comprehensive approach to embedding safeguarding activities into all organisational processes. The third element of effective safeguarding is people - ensuring that all staff are accountable for implementing the processes, and that there is regular learning and review of effectiveness (Keeping Children Safe, 2014). Guidance by Rockefeller Foundation and Oxfam America (2018) proposes making safeguarding processes systematic within evaluations, requiring an ethical review of evaluation methodology and a vulnerability assessment and including an evaluation question on safeguarding in every report.



There is also a need to consider local safeguarding legislation and attitudes. The safeguarding standards and policies of the organisation of the evaluator/researcher may differ from local standards introducing potential difficulties for the evaluator. For instance, attitudes to corporal punishment for children or gender-based violence differ between cultures and in some national legislation hitting children or violence towards women or girls may be acceptable. However, these standards are not consistent with safeguarding policies of most organisations based in the Global North. This raises an ethical challenge in deciding which – or whose - rules and processes to use. In considering ethical responses to safeguarding issues, evaluators need to consider how three “*overlapping domains of propriety*” are met as they relate to “*i) ensuring evaluators’ and participants’ ethical rights, responsibilities, and duties are met; ii) following systems of laws, regulations, and rules that take place at multiple national, tribal, federal, and local designations, and iii) ensuring the roles and duties inherent in evaluation professional practice are clear*” (Hopson, 2018:5).

Research and evaluation which involves children and women raises further questions relevant to the responsibilities of the evaluator or researcher in acting on disclosure of abuse or violence. Before starting evaluations, evaluators will need to plan how any safeguarding issues will be dealt with so that reporting processes are clear. Children and adult participants also need to understand that from the information provided to them prior to consent/assent that if they reveal something to the researchers that raises concern, then confidentiality will need to be breached. When working in cultures with different understandings of child protection, evaluators will need to consider thoughtfully how they will appropriately deal with any child abuse identified. (Keeping Children Safe, 2014; Powell et al, 2012; University of Sheffield, 2012). Reporting or acting on identified abuse requires the evaluator to defend the interests of the victim within the local context, so that remedies do not put the victim at further risk.

### *Sexual harassment and exploitation*

Sexual harassment and exploitation of local people - men, women, girls and boys - by the evaluators and researchers is not explicitly mentioned in the institutional research and evaluation guidance reviewed to date. However, it can and should be encompassed by the higher order ethical principle to do no harm, and addressed by the safeguarding processes used in evaluations, which would include risk assessment and mitigation, a reporting mechanism and organisational accountability to do no harm. As noted above, taking a whole system approach across the institution is central to effective safeguarding. Sexual exploitation must be properly addressed by organisational policies, process and accountabilities rather than guidance for research and ethics, although such guidance should be consistent with organisational policies. Evaluators should be asked to sign an organisation’s code of conduct as a standard part of the procurement process. The potential for and risk of sexual exploitation or abuse should be addressed in the risk assessment of the evaluation during the design phase.

### **Key points from section**

- Safeguarding includes protecting people (and for DFID, the environment) from unintended harm. It addresses preventing and responding to harm caused by sexual exploitation, abuse, harassment. It includes psychological as well physical harm.
- To be effective, safeguarding must be owned by the whole organisation and seen as everyone’s responsibility.
- Safeguarding policies need to consider how differences with local laws and customs will be addressed.
- Evaluators will need to plan how any safeguarding issues will be dealt with so that reporting processes are planned for and appropriate to context.

## Security of identity and security of data

Ethical guidance for research and evaluation often identifies the importance of guarding data that could identify participants. Identity should be protected throughout the research process, including respondent recruitment, data collection, data storage, analysis and reporting. Even where participants are not concerned about data disclosure, researchers should “*uphold principles of confidentiality and data protection and maintain the security of personal data and participants’ anonymity.*” (Government Social Research, 2011). Personal information may be collected only after informed consent has been provided by the individual in question, and that individual must be aware of the purpose of the collection. Confidentiality must be clearly explained to the individual before the information may be collected (UNFPA, 2013; UNEG, 2008).

The question of confidentiality extends beyond data; evaluators and researchers need to consider whether participating in research is likely to make people feel unsafe if other people know they are taking part, and whether taking part will draw unwanted attention or put people in danger (UNICEF, 2015). Questions on socially or politically sensitive issues, such as violence, abuse, prostitution, political views, HIV/AIDS, reproductive, sexual and mental health, other information that may be perceived as private or sensitive within the social context, opinions for which fear may exist of public disclosure, may all put participants at risk. This can be addressed by framing questions to avoid personal identification and addressing the inquiry within a broader set of questions.

Maintaining data security is also critically important. Data security has traditionally been focused on storing primary and secondary data collected securely, using password protection and encryption, and limiting access to it. Data security is also guarded by anonymising all data so that data cannot be associated with personal identifiers. This may include scrambling data or de-linking it from geographic or other identifiers. Qualitative data requires particular attention to avoid the source of comments being identified. There is some protection in international and national laws, since data and information activities must adhere to international law and standards of data protection and data security (Rockefeller Foundation and Oxfam America, 2018; PIM/OCHA, 2017). The General Data Protection Regulation (GDPR) provides some protection for the use of data profiling and mining within the European Union and European Economic Area. Girl Effect recommends undertaking a Data Privacy Impact Assessment (DPIA), as required by the GDPR, noting that in principle, elements of the DPIA could be undertaken in international and non-European contexts (Girl Effect, 2018).

With increased ease of collecting, analysing and sharing of data, made possible by faster information management technologies, wider use of web-based platforms, and data mining, new risks arise. Greater attention is required for the types of data security management outlined above and for the details provided in consent forms, and also for data sharing agreements with partner organisations. Images used in research methods or reports may be maliciously used, especially as images can now be more easily shared and misused online (Keeping Children Safe, 2014; Powell et al, 2012; University of Sheffield, 2012).

Lower and middle-income countries are at greater risk of data being shared without the individual’s consent and of exposure to loss of confidentiality. The GDPR applies to the data of citizens and residents of the EU and to all data which is processed in the UK and EU, so must be considered at an early stage. Although more countries are now introducing comparable legislation, it is from a low base. Greenleaf (2013: 11) shows that the overwhelming majority of states without privacy or data protection laws are low income or lower middle income countries. For example, in Sub-Saharan Africa in 2013, only eight states out of 55 had data protection law. The large data companies are powerful, and a lack of accountability may give rise to a culture of experimentation amongst technology giants (as has already been seen in the mass experiments conducted on users by various online services) to which countries with weaker data protection will be more vulnerable (Greenleaf, 2013).

The trend towards publishing data to make it accessible – open data – raises further questions. DFID has had since 2013 a commitment to open data in the interests of transparency and making data collected for research commissioned by DFID available for wider use globally<sup>1</sup>. Open access is intended to make data available to the developing world and increase the visibility of developing world research (DFID, 2013). Data to be shared includes, as well as published reports and peer reviewed articles, the raw data, sets and video, audio and images collected for research purposes.

Sharing data presents, however, some ethical challenges in that it will be even more important to consider how to safeguard anonymity of data including images and video to avoid risk of harm or negative impact to participants and their communities. There is a potential risk that researchers may constrain their research questions and samples to avoid risk, with a negative impact on the quality of the research.

There are also potential challenges in making data available concerning the quality of this data. When data is published on the web, there is a tendency to trust it as reliable and accurate. Some may be reliable, but not all. While DFID may have confidence in the data it publishes, some published data sets are less reliable, for instance data from countries where data sets are of poor quality, or where there has been some editing of data to provide a positive set of results. Open data platforms collecting and presenting datasets from various resources may have a duty to include some form of disclaimer about the quality /standard/accuracy of the data (Open Government Partnership, 2017).

### Key points from section

- Identity should be protected throughout the research process – including respondent recruitment, data collection, data storage, analysis and reporting.
- Maintaining data security is critically important.
- Greater attention is required for data security management with the advent of more technologies for mining data.
- An Open Data Policy introduces more risks to anonymity and data quality.

## Informed consent

### *Informed consent*

Informed consent to participation in research and evaluation is a central element of health and social science research ethics. Consent, as proposed by Gallagher (2009), is made up of four core principles:

- There must be an act of agreeing to participate, in written or verbal form.
- Consent can only be given if the participants have been informed about the research, and have an understanding of the research.
- Consent should be given voluntarily and without any form of coercion.
- Participants must be able to withdraw from the process at any time.

---

<sup>1</sup> The DFID Open Data policy only refers to requirements for research data, and it is therefore not clear whether evaluation data is subject to the same requirements.

In the context of qualitative research, consent can be seen as an ongoing process during the research process, so that the evaluator regularly reviews with participants the status of their consent during the research (Redwood & Todres, 2006; Maiter et al, 2008, Alderson & Morrow, 2011; Hood et al, 1996) and what they are consenting to. Risks need to be explicitly explained by the researcher/evaluator.

The conventional principle of informed consent assumes, “*research participants are individuated subjects who are more-or-less autonomous of social ties and obligations, literate, adult, and accustomed to relating to others in the context of formal contractual agreements*” (Butz, 2008: 242) This is, as noted by Chattopadhyay & De Vries (2008) the western approach to informed consent. It is a process that can be inappropriate in the context of the Global South as too much emphasis is given to the autonomy of the individual (ibid). This is argued to be particularly relevant to Africa, where there is a much stronger emphasis on individuals as part of a community. Forster (2010) notes that, in Africa, a person is identified by his or her interrelationships and not primarily by individualistic properties. The identity of the person is his or her place in the community. In Africa it is a matter of “*I participate, therefore I am.*” (ibid).

Internationally recognized ethical guidance can be seen as being inadequate because it does not address the cultural needs of indigenous people and other contexts (Gray et al, 2017). Within the realities of the socio-cultural setting, husbands, community elders and religious leaders may have a powerful influence on decision-making with regard to individual consent. There may therefore be a need potentially for a more considered presentation of research projects to avoid coercion. For instance, a study that was conducted by Hyder and Wali in 2006 with 203 researchers from Asia, Africa and South America found variation in how consent was obtained. Written consent from the individual was obtained in 62 percent of cases, approval from a village/community leader in 49 percent of cases, oral consent with a signature in 33 percent of cases. In 19 percent of cases informed consent for adults still required approval by a family member.

While there is consensus on the need to have a uniform global ethics guideline for the conduct of human research, it has become clear from this literature review that there are difficulties in applying ethical principles used in wealthy industrialized nations in different contexts. In developing countries poor education, poverty, socio-cultural influences on decision making and the consent process, especially for women and socially less powerful groups, pose challenges to obtaining freely given informed consent. (It should be noted that these factors also apply in the Global North where there are power imbalances.) There are also practical challenges in gaining informed consent by asking participants to sign their agreement. People who do not read or write will not be able to sign; and there are examples of individuals’ reluctance to sign agreements when there is suspicion of the implications of signing, previous bad experience of signing papers (for instance loss of land rights) or where signing papers is seen as potentially involving government or other official institutions. Government officials are also sometimes concerned about confidentiality and are reluctant to sign agreements (Abebe, 2009; Leaning, 2001). In such cases, asking people to sign consent forms is likely to negatively affect their participation; some guidance therefore suggests gaining recorded oral consent rather than written.

**Informed consent when people do not write**

The researcher developed a pictorial account of the work, using photographs; she also included some written text to avoid assumptions about participants’ literacy levels and to add an extra layer of communication. This was put onto a form on one page so that it was concise, cheap and easy to retain. She copied the forms and left them with people. Many participants brought the form to each research workshop, and many kept the form - along with the photographs they took - as evidence of their participation in the project.

(See Thompson, J., in ERIC 2013:141)

*Informed consent for adults with cognitive disability*

People with a disability are entitled to full and equitable participation in research, as outlined in the UN Convention on the Rights of Persons with Disabilities (2006). This includes people with a cognitive impairment, intellectual disability or a mental illness. Many people with a disability will have full capacity to participate in research and should not be deemed to be of high risk solely due to their disability. Appropriate methods of communication will need to be considered and found. These can include using braille or audio communication for people with visual or auditory impairment as well as using pictures to communicate with people with learning disabilities.<sup>2</sup>

Whether a person has the capacity to consent depends on the nature of their condition, including fluctuations in the condition, and the complexity of the research. Ideally, consent should also be witnessed by a person who has the capacity to fully comprehend the potential benefits and risks of the research, who is independent from the research team and, where possible, knows the participant and is familiar with his or her condition. Where potential participants are especially vulnerable, consideration should be given to the appointment of a participant advocate. However, at all times, participant resistance, discomfort or refusal to participate must be respected regardless of the views and opinions of others in the consent process (ACFID, 2017).

### *Informed consent/assent by children*

The Convention on the Rights of the Child (CRC, 1989) defines a child as a person below the age of 18 years, unless under national laws applicable to the child majority is attained earlier. Children are considered not to be capable of informed consent below 18, but instead can give their assent. UNICEF defines assent as “*the willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects.*” (UNICEF, 2015). For research involving children from about the age of seven, researchers commonly solicit both child *assent* and *parental permission*.” Assent is a child’s agreement to participate in research, which recognizes both emerging decisional capacity in children and that many children may not be fully capable of providing informed consent (Santelli, Haerizadeh & McGovern, 2017). Assent is not sufficient –explicit and recorded consent/permission from a parent or responsible adult is also required.

The issue of assent by children generates debate since some think that interpretation and application of ethical principles with different groups of children in different social contexts must take varying factors into account which requires complex decision-making (Alderson and Morrow, 2004; Clacherty & Donald, 2007). In many countries, access to children and young people is controlled by a range of individual and institutional gate-keepers, not just parents, but also community elders, such as chiefs and other traditional authorities. In some cases, parents and children will hesitate to participate in the research if such elders in their communities or families refuse their consent. In these contexts, it may be necessary to talk more broadly than ‘parental’ consent’ and researchers will need to think about how to work with such authorities (University of Sheffield, 2012).

---

<sup>2</sup> Please see: [www.peoplefirstltd.com](http://www.peoplefirstltd.com)



There are also, however, risks associated with parents' or others' consent. Parents/care givers/elders may give consent, against the wishes or interests of the child, or may coerce the child into participation. Children may give assent, without fully understanding the implications of disclosing information or participating, or out of a wish to please elders (Nyambedha, 2008). The risk of harm to children also needs to be balanced by the importance of supporting children's need to have the opportunity to give their views to research and evaluations relevant to their interests. The child's voice needs to be supported as well as protected. For assent to be valid "*the child must show evidence of understanding the purpose of the research, what he or she is to expect, and what will be expected*" (Ireland & Holloway, 1996:160;). Older children and adolescents are also subject to the need for parental consent, but they may well have greater capacity for assessing risk – against which needs to be balanced adolescents' greater propensity to take risks. The concepts of *evolving capacity* and *best interests (beneficence)* as enunciated in the UNCRC are useful in guiding ethical thinking about research with adolescents. Critical to these considerations is an understanding of adolescents' evolving capacities (Santelli et al, 2017).

There are some situations where it may be inappropriate or impossible to seek parental consent, for example when children are 'runaways' and homeless (Meade & Slesnick, 2002), living on the streets (Richter, Groft & Prinsloo, 2007; Vakaoti, 2009) or are displaced persons or orphans without parents/care givers. In these cases, it is possible to find ways of engaging children safely, to ensure their voices are heard; an exemption from standard consent guidance based on the potential benefits to the children will be required.

There are also strong reasons for finding ways to ensure that children can participate in evaluations. Ethical debates in the clinical sciences have tended to highlight protection of children from risk or direct harm, whereas in the social sciences, debates have focused on children's exclusion from research and argued for greater inclusion as a means of addressing power imbalances and ensuring that children's voices are heard (Dixon-Woods et al, 2006). Children constitute a significant proportion of the global population and in some communities they are the majority (Laws & Mann, 2004). Obtaining data from children themselves increases the possibility of presenting a picture that better reflects their experiences and situations and reduces misinterpretation by adults. Adult researchers may have less insight into the daily lives of children, particularly during and following humanitarian crises. Children also have the right to participate; Article 12 of the Convention on the Rights of the Child states that "*children have the right to participate in decision-making processes that may be relevant in their lives and to influence decisions taken in their regard... to share perspectives and recognises their potential to participate as citizens and actors of change*". (CRC, 1989). There is a risk of disadvantaging children if they are not involved /heard in humanitarian research since their needs will not be known resulting in policies and programmatic responses that fail to meet their needs and long-term development (Berman, et al, 2016).

#### Gaining consent where there are no parents

In sub-Saharan Africa, the AIDS epidemic has left children living in child-headed and youth-headed households. These are homes where all the adults have died, and the oldest caregiver is a child themselves, or a sibling aged 18-25 years. In these situations there is no parent or legal guardian able to give consent for the child to participate. For these situations, we allowed children to identify another trusted adult, such as a teacher or social worker, or an aunt or grandparent who could give consent for the children to participate.

Within the consent process it was also very important to ensure that children and adults truly understood all the information and expectations of research participation. Consent and information forms were read out in people's first languages, and were written in clear simple language without technical terms. At each stage in the research, children and their guardians or nominated adults were asked again for consent to participate.

(see Cluver. C., et al, in ERIC 2013:150)

## Key points from section

- Informed consent to participation in research and evaluation is a central element of health and social science research ethics.
- Individual consent does not always sit well in cultures where community authority is strong
- For different reasons written consent is not always feasible; other means such as recorded oral consent are needed.
- People with cognitive disabilities may need to be enabled to exercise their right to give consent and participate.
- Children may face particular risks of coercion, or influence; however it is important to ensure that children's voices are heard as this is a basic right, as established in the UNCRC.
- Where children have no parents to give consent, exemption from standard consent guidance based on the potential benefits to the children will be required.

## Humanitarian and conflict settings

Humanitarian and conflict settings introduce higher levels and quantity of ethical risks. *“Doing evaluation in conflict zones presents unique ethical challenges. Extreme context is infused with extreme ethical implications—more risks, greater risks, and greater consequences of all decisions and actions”*, (Duggan & Bush, 2014:18). There are two dimensions to ethics for the evaluation discussed by Duggan and Bush. First, the impact that the conflict or crisis has on the environmental conditions (physical, historical, social, cultural, political, and organizational) within which an evaluation is undertaken. Secondly, the impact of the conflict/crisis—its presence, legacy, or potentiality—on evaluators and evaluation stakeholders, on the conduct of an evaluation and on the communication and actual use of its findings. These can lead to ethical questions on the methodology – for instance have certain stakeholder groups been made invisible or excluded; are certain evaluation questions off limits? How will results be communicated and to whom? The influence of donors may come into play, for instance there may be a pressure to be seen to do good, even at the expense of the evaluation rigor and integrity. There is also great pressure on the evaluator, working in an emergency context in a constantly changing situation and facing personal risks of harm. Lastly, there is the challenge for evaluations of the evaluator “bunjee jumping in” to minimise time in a difficult and/ or hostile setting which limits evaluator opportunities to understand local context and sensitivities.

Ethical guidance for conflict and humanitarian situations has been limited, although the Research for Health in Humanitarian Crises tool 2017 (ELRHA) has helped to fill this gap. Other institutional guidelines may mention conflict setting, but rarely give detail, other than to require evaluators to be sensitive to conflict and humanitarian contexts. The Organization for Economic Cooperation and Development has published a handbook to help address the need (OECD, 2012). There is little discussion of ethics in conflict settings in the wider literature. However, the point is made by Duggan and Bush (as above) that detailed guidelines may not be useful in a crisis setting given that no list could be sufficient given the variety of permutations of ethical challenges and the variability of contexts in which they arise. They emphasise the importance of (and pressure on) the evaluator's role in identifying ethical issues and in identifying solutions to ethical risks, including stopping the evaluation. IRBs/RECs, and ethical advisory committees can also help, where they are in place.

Every research project should carefully identify the vulnerabilities likely to exist in their research context and delineate how these will be addressed in their research design and implementation, but particular attention needs to be given to the specific challenges of working with people in crisis in a very vulnerable situation. The urgency of working in emergency situations introduces a risk that standard ethical guidance may be ignored. Research in these contexts is noted sometimes as not being rigorous in use of ethical processes and standards, due to the lack of time in an emergency situation

(Blanchet, et al, 2013). At the same time, it may be essential to carry out research promptly in order to benefit affected communities. Médecins sans Frontières addresses this dilemma specifically in its guidance (MSF 2013). Médecins sans Frontières requires all its research involving human subjects to be submitted to its Ethics Review Board (ERB) for approval; in the case of emergency research, the ERB is willing to pre-approve generic proposals. These are then completed for expedited review with a 48 hour turn around. Finding local ERBs to work with may not be possible as they may not exist (Ford, et al, 2009).

Evaluations and research in humanitarian and conflict settings raise the same ethical issues as other settings, but with greater acuity. If research is to be undertaken with refugees, there needs to be a comprehensive understanding as to why the research needs to be undertaken, especially as the people affected by humanitarian crisis are vulnerable. The assessment of whether the benefits of participation outweigh the risks is critical; it also needs to be informed by a robust understanding of the context, and by an assessment of people’s vulnerabilities. People in humanitarian settings will face challenges with meeting basic needs, and they are likely to be suffering from some form of psychological trauma (Hunt, 2017; Jacobsen & Landau, 2003:186). The ELRHA 2017 guidance notes the importance of balancing the risk to participants against their desire to take part and willingness to accept the risks involved, and emphasises the researcher’s responsibility to take due account of vulnerability and contribute to ameliorating it, not reinforcing it (ELRHA, 2017).

Research with children in humanitarian settings is particularly sensitive, given that they are likely to have experienced psychological and/or physical trauma, and are therefore particularly vulnerable. Research methods must be sensitive and responsive to the child’s experiences, needs and situation. In the context of humanitarian emergencies, there can be issues/tensions between the rights of a child to participate in research and the ability of the researcher to ensure that children do not come to ‘harm’ and protecting children from harm must take precedence over them being able to participate in research (Bennouna, et al, 2017). The dynamics of conducting research with children in emergencies is significantly different to conducting research with children in non-emergency situations. For children in emergencies, it can be hard to ascertain the age and history of a child, as well as to obtain consent from a guardian for them to participate in a research activity. The need to ensure that consent is regularly renegotiated with the child is critical since their risk of harm may change day to day in a volatile situation. Furthermore, the researcher/evaluator may not be in a position to ensure that the children who they work with are safe, safe from reprisal or in some cases harm (Hart & Tyrer, 2006). Given the risk of sexual exploitation and abuse in humanitarian settings, there is merit in ensuring that there is a full safeguarding and vulnerability assessment undertaken, and that a question on safeguarding is included (Berman, et al, 2017; Rockefeller Foundation and Oxfam America, 2018).

**Key points from section**

- Evaluations and research in humanitarian and conflict settings raise the same ethical issues as in other settings, but with greater acuity.
- Ethical risks are posed by the specific context of the conflict or crisis.
- Whether the benefits of participation outweigh the risks has to be carefully assessed in relation to individuals’/communities’ context specific vulnerabilities.
- The researcher’s responsibility is to take due account of the vulnerability of those involved in the research and evaluation and contribute to ameliorating it, not reinforcing it.
- There is also a responsibility to the wellbeing and safety of the researcher/evaluator.



## Honesty, competence, integrity and accountability

### *Evaluators'/researchers' ethical behaviours and capacity*

Ethical principles and standards for researchers'/evaluators' personal conduct and competence in designing and conducting the research/evaluation are also critical to ensuring that work has integrity. The professionalism, competence and integrity of the researcher/evaluator is noted as important, both in contributing to delivering technically competent work, but also in defining standards of moral and honest behaviour. The American Evaluation Society guidance expresses this as: *"Evaluators behave with honesty and transparency in order to ensure the integrity of the evaluation."* (AES, 2018). This identifies the importance of evaluators' behaviours and personal morality in delivering ethical evaluations.

Some guidelines stipulate that a researcher/evaluator has a responsibility to ensure that they do the 'right' thing by potential research participants and take a moral approach. However, as discussed by Johnsson, et al (2014) ethics guidance cannot educate or guide researchers in moral and professionally appropriate behaviour unless they already possess capacity for moral judgment and for being able to conduct research in a responsible 'right' manner. Researchers and evaluators therefore need to have the capacity for, and be able to demonstrate, professional judgment. They also need to have a shared understanding "right", which poses a challenge when working across cultures, since morals and ethical standards are not universally shared. This challenge raises the question of how researchers can be held accountable for their behaviour when undertaking field work, and how ethical standards are made explicit. A researcher's moral judgment is not generally referred to in guidance/standards; it appears often to be assumed that the researcher/evaluator will do the 'right' and moral thing when undertaking research. Given the lack of moral universality, this can be problematic.

Guidance for research and evaluations of development and humanitarian work also refers to the importance of knowledge of and sensitivity to the country culture, values and context (e.g. ACFID 2017; MSF 2013; UNFPA, 2019). An external evaluator/researcher, potentially from a different culture, will have assumptions, values and understanding of context that are likely to be different to that of local communities, and/or of groups different to the researcher for instance due to gender, religion, age, physical ability. A core requirement for an evaluator/researcher is to understand and be aware of the perspectives of others, in designing the research questions and methods. Evaluators may need to be trained in working with potentially vulnerable people, or people from different cultures.

When undertaking research, especially in the Global South, there is a need to be sensitive to the local environment and to cultures with which a researcher may not be familiar. It is also important to take into consideration the possibility of intrusion and that researchers who are not from the local context do not have a 'right' to work with people in the Global South (Laws, et al 2003). There will also be power gradients between researchers'/evaluators and research participants (Scheyvens & Nowark, 2003). As argued by Madden (2010), in the context of evaluations and research there is a need for reflective practice. Reflexivity requires that the researcher must not forget that they will always maintain some sense of the outsider, despite the fact that they may become familiar with the people who they are working with; that there are disparities in power and status between themselves and the research participants; and whether they have capacity to do the research (Flyvbjerg, cited in Emslie, 2009:419). Reflexivity influences the researcher's comportment as well as decisions that they make take. Being reflexive is *'both a skill and a virtue'* (Moore, 2012:67). Emotional openness to a research participant that can also guide the research process, and enhance it. A level of trust and confidence between researcher and participant can benefit the research/evaluation (May, 2001).

There is a body of thought that questions whether ethics can be reduced to a codified set of principles that can be systematically followed and whether ethics in research more than following a basic set of rules (Hill, 2005; Gallagher, 2009; Alderson and Morrow, 2011). Duggan and Bush echo this when they note the importance of gut reaction in knowing what the right thing to do is when faced with an ethical challenge, and write, “*ethical challenges are anything but static or one dimensional. Rather, they are dynamic, omnipresent, multidimensional, and abundant. No list could ever be comprehensive, given the variety of permutations that ethical challenges might assume and the variability of the contexts within which they arise*” (Duggan & Bush, 2014:3). There is therefore a question as to how far ethics codes and guidance can encompass right behaviour, and the importance of evaluators understanding the key ethical principles governing their work rather than the standards they need to follow. Ethics is not a tick box exercise.

### *Integrity and merit of the work*

Research and evaluations which deliver benefits also need to demonstrate their integrity and quality. Guidance refers to the importance of ensuring that the research or evaluation is independent, impartial, credible and honest (UNEG, 2008; AES, 2018; ONS, 2008; WHO, 2017; UNFPA 2019). Equally frequent is the reference to the quality of research design to deliver the intended results, with good alignment between aims, questions and methodology, and the requirement to have competent and professional researchers and evaluators who have integrity. Integrity includes “*intellectual and moral honesty in proposing, conducting, and reporting research... and truthfulness and responsible conduct*” (WHO, 2017). Integrity therefore extends across the research cycle, from inception to dissemination, and show the important role of the evaluator/researcher in defending and holding to the evidence generated, regardless of any pressures to vary or suppress findings.

### **Key points from section**

- Researchers/evaluators require capacity for moral judgment and for being able to conduct research in a responsible ‘right’ manner.
- Researchers require sensitivity to context and the capacity to work reflexively.
- Ethics codes and guidance can lay down expectations but many decisions will be made in the moment and therefore evaluators and researchers need to have a solid foundation in ‘right behaviour’, based on robust training and experience.
- Research/evaluation needs to demonstrate that it is independent, impartial, credible, and has merit and integrity.

# Conclusions

The review focus has been on aspects of ethics which are relevant to DFID in developing and using ethics guidance in its evaluation, research and monitoring work and in its role as a commissioner for such work. The conclusions below are therefore written with this in mind.

1. There are a large number of relevant ethical guidance documents in existence with a range of different functions, which are sometimes ambiguous or confusing.

Learning point: For guidance to be fully used and useful, it is critically important to have institutional clarity on the purpose and use of ethics guidance as well as on who must or should use it, when and how.

2. When the moral principles which frame guidance are not clearly stated, it is more difficult to clarify the rationale for ethical standards given and to test ethical challenges.

Learning point: With clear principles as a reference point, standards can flow transparently from them. The principles can be used as the touchstone against which to assess challenges, allowing greater context specific flexibility when this is appropriate, for instance in a conflict setting, or when child participants have no available guardians to give consent for participation.

3. Ethical principles and standards need to be clearly stated within quality assurance standards and used to assess all research and evaluations, unless an IRB assessment is undertaken.

Learning point: Ethics need to be operationalised. The first step is to ensure that terms of reference, inception reports and reports are explicitly assessed in terms of ethical standards, risk assessment and mitigation, and that this is externally scrutinised and approved.

4. Evaluators and researchers require personal capacity for moral judgement to identify the key ethical issues and how they will be addressed.

Learning point: Evaluators, researchers and commissioners are responsible for the ethical quality of work from inception through conduct and dissemination, for identifying and mitigating ethical challenges, and defending the integrity of the work. Within an organisational context, it is therefore important to ensure that staff are trained and aware of ethics commitments and guidance, and accountable for them. This can be better facilitated when there is an organisation -wide ethical culture and way of working.

5. Safeguarding people from harm is central to the principle of minimising harm (non-maleficence), and therefore must be addressed in all evaluations/research/ monitoring.

Learning point: For DFID to ensure that safeguarding is effective, it needs to go further than a compliance exercise with contractors. Proposals need to show how safeguarding is implemented and adapted to context, and that there are robust safeguarding processes in place, which staff and subcontractors are trained in using.

# Annex 1: Bibliography

**Please also see the extensive bibliography compiled by Leslie Groves for her review of ethics for DFID in 2015 (Groves, 2016).**

<https://ethicsinevaluationandresearch.wordpress.com/bibliography-of-relevant-documents/>

ACFID (Australian Council for International Development). (2017) Principles and Guidelines for ethical research and evaluation in development. Available at: [https://acfid.asn.au/sites/site.acfid/files/resource\\_document/ACFID\\_RDI%20Principles%20and%20Guidelines%20for%20ethical%20research12-07-2017.pdf](https://acfid.asn.au/sites/site.acfid/files/resource_document/ACFID_RDI%20Principles%20and%20Guidelines%20for%20ethical%20research12-07-2017.pdf) (Accessed, February 17<sup>th</sup> 2019).

AES, American Evaluation Society (2018) Guiding Principles (2018) Update. Available at: <https://www.eval.org/p/cm/ld/fid=51> (Accessed, February 17<sup>th</sup> 2019).

Alderson, P. and Morrow, V. (2004). *Ethics, social research and consulting with children and young people*. Barkingside. Barnardos.

Alderson, P. and Morrow, V. (2011) *The Ethics of Research with Children and Young people*. (Second Ed) Chennai. Sage.

Banks, S. et al. (2013) Everyday ethics in community-based participatory research. *Contemporary Social Science*. 8 (3): 263-277.

Barnes, J. (1979) *Who Should Know What? Social Science, Privacy and Ethics*. Harmondsworth. Penguin.

Barnett, C. and Camfield, L. (2016) Ethics in Evaluation. *Journal of Development Effectiveness*. 8 (4): 528-534.

Beazley H, et al. (2009) The right to be properly researched: Research with children in a messy, real world. *Child Geographies*. 7 (4) :365–78.

Bennouna, C. et al. (2017) Ethical considerations for children’s participation in data collection activities during humanitarian emergencies: A Delphi review. *Conflict and Health*. 11 (5): 1-15.

Berman, G., Hart, J., O’Mathúna, D., Mattellone, E., Potts, A., O’Kane, C., Shusterman, J., and Tanner, T. (2016). What We Know about Ethical Research Involving Children in Humanitarian Settings: An overview of principles, the literature and case studies, Innocenti Working Paper No. 2016-18, UNICEF Office of Research, Florence.

Blanchet, K. et al. (2013) An evidence review of research on health interventions in humanitarian crisis. Available at: <http://researchonline.lshtm.ac.uk/2172838/1/What-is-the-evidence-on-the-economic-impacts-of-integrated-care.pdf> (Accessed, 4<sup>th</sup> February 2019).

Bhutta, ZA, (2002) Ethics in international health research: a perspective from the developing world. *Bulletin of the World Health Organization*. 80 (2): 114-120.

Bloom, M. (2010) “Client-Centered Evaluation: Ethics for 21st Century.” *Journal of Social Work Values and Ethics*. 7 (1): 1-7.

Boyden, J, and Ennew, J. (1997) *Children in focus: a manual for participatory research with children*. Stockholm. Save the Children Sweden.

Butz, D. (2008) Sidelined by the guidelines: Reflections on the limitations of standard informed consent procedures for the conduct of ethical research. *ACME: An International E-Journal for Critical Geographies* 7(2). Available at: <http://www.acme-journal.org/vol7/DBu.pdf>

Cahill, H, et al. (2010) *Adolescents in emergencies*. Parkville. University of Melbourne.

Chilisa, B., Major, T.E., Gaotlhobogwe, M., and Mokgolodi, H. (2016). Decolonizing and indigenizing evaluation practice in Africa: Toward African relational evaluation approaches. *Canadian Journal of Program Evaluation*, 30(3), 313-328.

Cochrane, L. et al. (2018) The case for local ethics oversight in international development research. *Canadian Journal of Bioethics/Revue canadienne de bioéthique*. 1(1):8-16.

Chambers, R. (2007) *Who counts? The quiet revolution of participation and numbers*. IDS Working Paper 296. Brighton. University of Sussex.

Chattopadhyay, S. and De Vries, R. (2008) Bioethical concerns are global, bioethics is western *Eubios Journal of Asian and International Bioethics*. 18(4): 106–109.

Chattopadhyay, S, et al. (2017) A question of social justice: how policies of profit negate engagement of developing world bioethicists and undermine Global bioethics. *American Journal of Bioethics*. 17(10): 3-14.

CIDA (Canadian International Development Agency. (2004). *CIDA Evaluation Guide*, CIDA, Ottawa, Canada.

Clacherty, G. and Donald, D. (2007). Child participation in research: Reflections on ethical challenges in the Southern African context. *African Journal of AIDS Research*. 6: 147-156.

Cleaton-Jones, P. and Wassenaar, D. (2010) Protection of human participants in health research- a comparison of some UD Federal Regulations and South African Research Ethics guidelines. *South African Medical Journal*. 100 (11): 710-716.

Cocks, A. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood*. 13: 247-266.

Corbridge, S. (1998) Development Ethics: distance, difference, plausibility. *Ethics, Place and Environment*. 1 (1): 35-53.

CRC. (1989) Convention on the Rights of the Child. Available at: [https://www.unicef.org/uk/wp-content/uploads/2010/05/UNCRC\\_united\\_nations\\_convention\\_on\\_the\\_rights\\_of\\_the\\_child.pdf](https://www.unicef.org/uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf) (Accessed, January 17<sup>th</sup> 2019).

DFAT. (2017) DFAT monitoring and evaluation standards. Available at: <https://dfat.gov.au/about-us/publications/documents/monitoring-evaluation-standards.pdf> (Accessed, January 17<sup>th</sup> 2019).

DFID (2011). DFID ethics principles for research and evaluation: <https://www.gov.uk/government/publications/dfid-ethics-principles-for-research-and-evaluation>

- DFID. (2013) DFID Research Open and Enhanced Access Policy, DFID, London, UK  
<https://www.gov.uk/government/publications/dfid-research-open-and-enhanced-access-policy>
- DFID. (2017) Smart Guide: Environmental and Social Safeguards. Unpublished document.
- DFID. (2018) Enhanced Due diligence for External Partners.  
<https://www.gov.uk/government/publications/dfid-enhanced-due-diligence-safeguarding-for-external-partners>
- DFID. (2019) Safer schools: Addressing school violence through education programming.
- Dixon-Woods, M. Young, B. and Ross, E. (2006). Researching chronic childhood illness: The example of childhood cancer. *Chronic Illness*. 2:165-177.
- Duggan, C. and Bush, K. (2014). The Ethical Tipping Points of Evaluators in Conflict Zones. *American Journal of Evaluation*. 35 (4): 485-506.
- Dyregrov, K. Dyregrov, A. and Raundalen M. (2010) Refugee families' experience of research participation. *J Trauma Stress*. 13(3):413–26.
- Ebrahim, H. (2010). Situated ethics: Possibilities for young children as research participants in the South African context. *Early Child Development and Care*. 180: 289-298.
- Emond, J. (2018) Doing no harm in monitoring and evaluation. A safeguarding perspective. Unpublished.
- ELRHA. (2017) Research for Health in Humanitarian Crises. Available at:  
<https://www.elrha.org/wp-content/uploads/2017/06/R2HC-Ethics-Framework-2.0-Introduction.pdf> (Accessed, January 13th 2019).
- ESRC. (2019) Available at: <https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-questions/what-are-the-ethical-considerations-of-disseminating-findings/> (Accessed, March 1<sup>st</sup> 2019).
- Etta. F. (2018) *Safeguarding Oxfam's Failures: Ethical MEL Practice?* Unpublished, at date of writing, to be published by Oxfam America.
- Ford, N. et al (2009) Ethics of conducting research in conflict settings. *Conflict and Health*. 3 (7): 1-9.
- Forster, D. (2010). African relational ontology, individual identity, and Christian theology: An African theology contribution towards an integrated relational ontology identity. *Theology*. 113 (874): 243 – 253.
- Gallagher, M. (2009) Ethics. In Tinsdall, E.K, Davies, J and Gallagher, M.(eds) *Researching with children and young people: Research design, methods and analysis*. London. Sage.
- Gillion, R. (1994) Medical ethics: four principles and attention to scope. *BMJ*. 309: 184-188.
- Gyekye, K. (2010) African ethics. Available at: <https://plato.stanford.edu/entries/african-ethics/> (Accessed February, 4<sup>th</sup> 2019).



Gibbs L, et al. (2013) Research with, by, for and about children: Lessons from disaster contexts. *Global Studies Child.* 3(2):129–41.

Girl Effect. (2018) Digital Safeguarding Tips and Guidance Available at: <https://www.girleffect.org/stories/digital-safeguarding/> (Accessed, March 1<sup>st</sup> 2019).

Government Social Research (GSR). (2011) GSR Professional Guidance Ethical Assurance for Social Research in Government. Government Social Research Service Unit, London, UK

Graham, A. et al. (2013) *Ethical research involving children*. Florence: UNICEF Office of Research–Innocenti.

Gray, B. et al. (2017) Are research ethics guidelines culturally competent? *Research Ethics.* 13 (1): 23-41.

Greenleaf, G., (2013) *Data protection in a globalised network*, in Research Handbook on Governance of the Internet , ed. Ian Brown DOI: <https://doi.org/10.4337/9781849805049.00018>

Groves, L. (2015) *Beneficiary Feedback in Evaluation*. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/428382/Beneficiary-Feedback-Feb15a.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/428382/Beneficiary-Feedback-Feb15a.pdf) (Accessed, 5<sup>th</sup> February 2019).

Groves, L. (2016) *Review of Ethics Principles and Guidance in Evaluation and Research*. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/524635/Ethics-principles-report-2016.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/524635/Ethics-principles-report-2016.pdf) (Accessed, 5<sup>th</sup> May 2018).

Hart, J. and Tyrer, B.(2006) *Research with children living in situations of armed conflict: Concepts, ethics and methods*. Oxford. Oxford University Press.

Hill, M. (2005). Ethical considerations in researching children’s experiences. In S. Greene and D. Hogan, (eds). *Researching children’s experience*. London: Sage Publications. pp. 61-86.

Hopson, R. and Cram, F. (2018) *Tackling Wicked Problems in Complex Ecologies: The Role of Evaluation*, Stanford University Press, USA.

Hopson, R. (2018) *Addressing Oxfam’s Safeguarding Failures and Ethical Implications for Evaluation Practice*. Department of Educational Psychology, College of Education, University of Illinois. Urbana Champaign, unpublished at date of writing, to be published by Oxfam America.

Hunt, M. (2017) Ethics OF and ethics IN humanitarian research. Available at: <http://www.evidenceaid.org/ethics-of-and-ethics-in-humanitarian-research/> (Accessed, 27 February 2019).

Hyder, A. and Wali, S. (2006) Informed consent and collaborative research: perspectives from the developing world. *Developing World Bioethics.* 6:(1) 33-40.

Laws, S. (2003) *Research for Development*. India. SAGE.

Leaning, J. (2001) Ethics of research in refugee populations. *Lancet.* 357: 1432-33.

- Lindsay, G. (2000). Researching children's perspectives: ethical issues. In Lewis, A. and Lindsay, G. (Eds.) *Researching children's perspectives*. Buckingham. Open University Press. pp. 3-20.
- Ireland, L. & Holloway, I. (1996) Qualitative Research with Children. *Children and Society*. 10: (2) 155-164.
- Jacobsen, K. and Landau, L. B. (2003) 'The dual imperative in refugee research: Some methodological and ethical considerations in research on forced migration' *Disasters*. 27(3): 185–206.
- Johnsson, L. et al. (2014) Making researchers moral: Why trustworthiness requires more than ethics guidelines and review. *Research Ethics*. 10 (1): 29-46.
- Katz, V.R. (2006) The Tuskegee Legacy Project: Willingness of minorities to participate in biomedical research. *Journal of Health Care for the Poor and Underserved*. 17 (4): 698-715.
- Keeping Children Safe: Child Safeguarding Standards and how to implement them (2014) [www.keepingchildrensafe.org.uk/resources](http://www.keepingchildrensafe.org.uk/resources)
- King, N. and Churchill, L. (2000). Ethical principles guiding research in child and adolescent subjects. *Journal of Interpersonal Violence*. 7: 710-724.
- Kruger, M. Ndebele, P. and Horn, L. (2014) *Research Ethics in Africa. A Resource for Research Ethics Committees*. South Africa. Sun Press.
- Mackenzie, C. McDowell, C. and Pittaway, E. (2007) 'Beyond "do no harm": The challenge of constructing ethical relationships in refugee research', *Journal of Refugee Studies*. 20(2): 299–319.
- Maiter, S. et al. (2008) 'Reciprocity: An ethics for community-based participatory action research', *Action Research*. 6(3): 305–25.
- Makhoul, J. et al. (2018) A scoping review of reporting 'Ethical Research Practices' in research conducted among refugees and war-affected populations in the Arab world. *BMC Medical Ethics*. 19 (36): 1-9.
- Mandushani, H.D.P. (2016) Ethical Issues in Social Science Research: A Review. *Journal of Social Statistics*. 26-33.
- May, T. (2001) *Social Research, Issues, methods and process*. 3<sup>rd</sup> ed. Great Britain. Open University Press.
- Melé, D.N. and Sánchez-Runde, C. (2013) Cultural diversity and universal ethics in a global world. *Journal of Business Ethics*. 116(4): 681–687.
- Mezinska, S. et al. (2016) Research in disaster settings: a systematic qualitative review of ethical guidelines. *BMC Medical Ethics*. 17 (26): 1-11.
- MFS, (2013) MSF research Framework- Guidance Document. Available at: [https://fieldresearch.msf.org/bitstream/handle/10144/305288/MSF%20Research%20Ethics%20Framework\\_Guidance%20document%20%28Dec2013%29.pdf?sequence=5&disAllowed=y](https://fieldresearch.msf.org/bitstream/handle/10144/305288/MSF%20Research%20Ethics%20Framework_Guidance%20document%20%28Dec2013%29.pdf?sequence=5&disAllowed=y) (Accessed, February 2017).



Molyneux, C.S and Geissler, P.W. (2008) Ethics and ethnography of medical research in Africa. *Social Science and Medicine*. 67 (5): 685-95.

Morris, N. (2015) Providing ethical guidance for collaborative research in developing countries. *Research Ethics*. 11 (4): 211-235.

Msoroka, S. and Amunden, D. (2018) One size fits not quit all: Universal research ethics with diversity. *Research Ethics*. 14 (3): 1-17.

Nayfeh, A. and Charron, D. (2018) Ethical challenges faced by development researchers in low and middle-income countries. *Canadian Journal of Bioethics/Revue canadienne de bioéthique*, 1 (1): 1-4.

NHS Health Research Agency. (2017)  
[http://www.hra-decisiontools.org.uk/research/docs/DefiningResearchTable\\_Oct2017-1.pdf](http://www.hra-decisiontools.org.uk/research/docs/DefiningResearchTable_Oct2017-1.pdf)

Nordenstam, T (1968) *Sudanese ethics*. Uppsala: Nordiska Afrikainstitute.

Nyambedha, E. (2008). Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya. *Social Science & Medicine*, 67, 771-779.

Patton, M. Q. (2014) *Evaluation Flash Cards, Embedding Evaluative Thinking In Organizational Culture*. St Paul, MN: Otto Bremer Foundation.

OECD (2012), Evaluating Peacebuilding Activities in Settings of Conflict and Fragility: Improving Learning for Results. Available at: <http://dx.doi.org/10.1787/9789264106802-en> (Accessed, 13<sup>th</sup> December 2018).

Open Government Partnership (2017) The Ethics of Working With Open Data in Closed Societies. Available at: <https://www.opengovpartnership.org/stories/ethics-of-working-open-data-closed-societies> (Accessed, 1<sup>st</sup> March 2019).

ONS. (2018) Code of Practice for Statistics. Ensuring official statistics serve the public. Available at: <https://www.statisticsauthority.gov.uk/wp-content/uploads/2017/07/DRAFT-Code-2.pdf> (Accessed, 13<sup>th</sup> December 2018).

Oxfam. (2012) Undertaking Research Ethics. Available at: <https://policy-practice.oxfam.org.uk/our-approach/research/research-guidelines> (Accessed, 13<sup>th</sup> December 2018).

PIM (Protection for Information Management). (2017) Framework for data sharing in practice. OCHA and PIM. Available at: <https://pim.guide/uncategorized/ocha-pim-framework-data-sharing-practice-part/> (Accessed, 1<sup>st</sup> March, 2019).

Pittaway, E. and Bartolomei, L. (2003) Women at Risk Field Research Report: Thailand 2003, Sydney, Centre for Refugee Research, University of New South Wales.

Powell, M.A., Fitzgerald, R., Taylor, N.J., & Graham, A. (2012). International Literature Review: Ethical Issues in Undertaking Research with Children and Young People (Literature review for the Childwatch International Research Network). Lismore: Southern Cross University, Centre for Children and Young People / Dunedin: University of Otago, Centre for Research on Children and Families

Rockefeller Foundation and Oxfam America. (2018). Doing No Harm in Monitoring and Evaluation. Unpublished, meeting report, shared by Oxfam America.

Raifman, J. et al. (2018) How well are aid agencies evaluating programs? An assessment of the quality of Global health evaluations. *Journal of Development Effectiveness*. 10 (2): 277-289.

Redwood, S. and Todres, L. (2006) 'Exploring the ethical imagination: Conversation as practice versus committee as gatekeeper', *Forum Qualitative Sozialforschung/Forum: Qualitative Social*.

Ross, B. et al. (2018) Getting the Word Out: New Approaches for Disseminating Public Health Science. *Public Health Management and Practice*. 24 (2): 102-111.

Santelli, J. Haerizadeh, S. and McGovern, T. (2017) Inclusion with Protection: Obtaining informed consent when conducting research with adolescents, *Innocenti Research Brief*. UNICEF,

Save the Children UK, (2018a). Child Safeguarding Policy, Save the Children UK, London.

Save the Children UK, (2018b). Process Guidance for Studies, Save the Children UK, London.

Scheyvens, H. and Nowark, B. (eds) *Development Fieldwork. A Practical Guide*. Trowbridge. Sage.

Siriwardhana, C. et al. (2017) R2HC Ethics Framework 2.0. Available at: [https://www.elrha.org/wp-content/uploads/2017/06/R2HC-Ethics-Framework-2.0\\_Introduction.pdf](https://www.elrha.org/wp-content/uploads/2017/06/R2HC-Ethics-Framework-2.0_Introduction.pdf) (Accessed, 10<sup>th</sup> January).

Social Research Action. (2003) . Available at: Ethical Guidelines. <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf> (Accessed, 10<sup>th</sup> January).

Spriggs, M. (2007). When "risk" and "benefit" are open to interpretation – As is generally the case. *American Journal of Bioethics*. 7: 17-19.

The Research Ethics Guidebook (no date) Dissemination and 'impact' Available at: <http://www.ethicsguidebook.ac.uk/Dissemination-and-impact-summing-up-183> (Accessed, 4<sup>th</sup> March 2019).

Thomas, S. and Byford, S. (2003) Research with unaccompanied children seeking asylum. *Br Med J*. 327 (7428) : 1400.

Tisdall, E.K., Davis, J., and Gallagher, M. (2009). *Researching with children and young people: Research design, methods and analysis*. London. Sage Publications.

Uganda Evaluation Association. (2014) Uganda Evaluation Standards. Available at: <https://ecduganda.files.wordpress.com/2014/05/uganda-evaluation-standards.pdf> (Accessed, March 2<sup>nd</sup> 2019).

UKCDRR, (2018) International Development Research Funders Statement on Safeguarding. Available at: <https://www.ukcdr.org.uk/resource/international-development-research-funders-statement-on-safeguarding/> (Accessed, 1<sup>st</sup> March 2019).

UNEG, (2008) <http://www.unevaluation.org/document/detail/102> Available at: <http://www.unevaluation.org/document/detail/102> (Accessed, 14<sup>th</sup> December 2019).

UNFPA (2019) UNFPA Handbook How to Design and Conduct a Country Programme Evaluation at UNFPA Independent Evaluation Office, UNFPA, New York  
<https://www.unfpa.org/EvaluationHandbook>

UNICEF (2015) UNICEF procedure for ethical standards in research, evaluation, data collection and analysis. Available at: [https://www.unicef.org/supply/files/ATTACHMENT\\_IV-UNICEF\\_Procedure\\_for\\_Ethical\\_Standards.PDF](https://www.unicef.org/supply/files/ATTACHMENT_IV-UNICEF_Procedure_for_Ethical_Standards.PDF) (Accessed, 1<sup>st</sup> March 2019).

University of Sheffield. (2012) Specialist Research Ethics Guidance Paper, Ethical Considerations in research with children and young people, University of Sheffield Research Ethics Committee. Available at: <https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/special-guidance/papers> (Accessed, 1<sup>st</sup> March 2019).

WHO, (2017) Code of conduct for responsible Research. Available at: <https://www.who.int/about/ethics/code-of-conduct-for-responsible-research> (Accessed, 1<sup>st</sup> December 2019).

Whitmore, E. et al (2013) Embedding improvements, Lived experiences, and social justice in evaluation practice. In: Shaw, I, Green, J and Mark, M. (eds) *Handbook of Evaluation. Policies, Programs and Practices*. Sage. Trowbridge. P341.

Zwanikken, P. and Oosterhoff, P. (2011) Why research committee for social science? Reflections on three years of experience at the Royal Tropical Institute, Amsterdam. *MEDISCHE ANTROPOLOGIE*. 23 (1): 165-181.