

# Research ethics in complex contexts

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# My background

- **Student** in Oslo, Tromsø, Frankrike, Somalia
- **Aid worker** in Bosnia
- **Academic in Norway and UK** (IoP, KC, UiT, UiB og OsloMet) med prosjekter i Sudan, Nepal, Niger, Guatemala, Uganda, Norge
- **Clinician** in Tromsø, Frankrike, Oslo
- **Bureacrat**
- **Diplomat**
- **Leader**
- **Vounteer and board member**

# For reflection

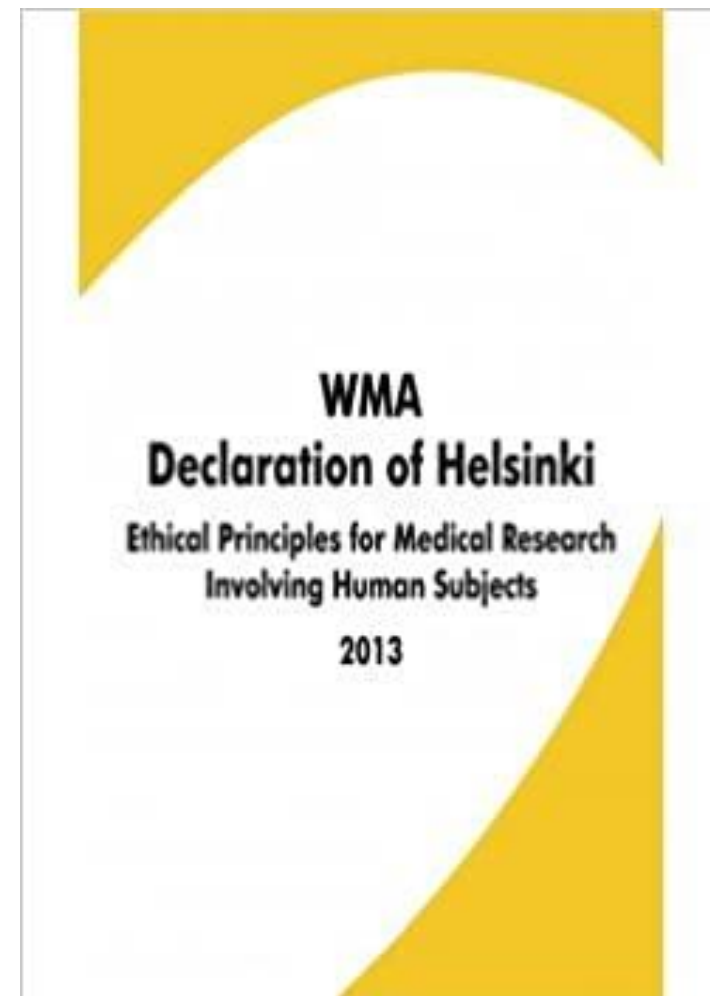
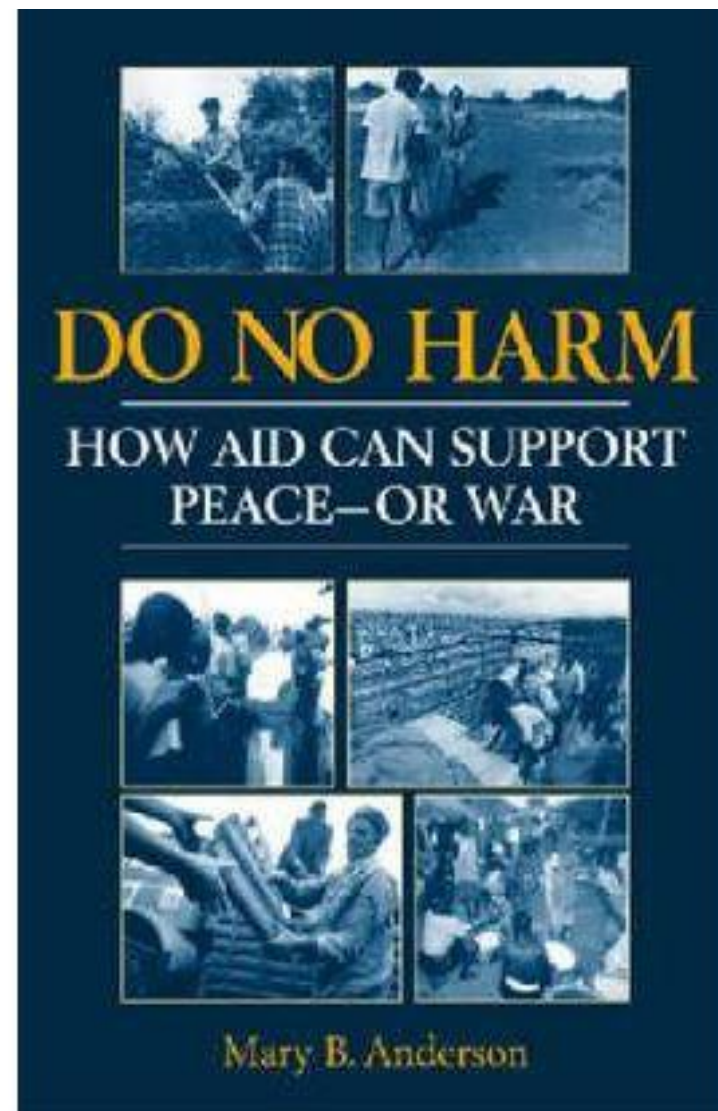
- Why focus on research ethics?
- How is research quality and ethics linked?
- What are «complex contexts»?
- Who should/should not do it?
- What research should be done? And should not be done?



# Global Mental Health Ethics

Allen R. Dyer  
Brandon A. Kohrt  
Philip J. Candilis  
*Editors*

 Springer





# “Complex contexts”

- Poverty, inequality, humanitarian contexts
- Differences in language, culture
- Vulnerable populations
- Sensitive issues
- Disrupted protection systems and weak systems for detecting and reporting abuse



## Complex contexts and power inequality

- When people rely on humanitarian actors to meet basic needs, the unequal power relationships between those delivering services and doing research, and those receiving services or being subject to research, increase the risk for abuse or exploitation of the affected population.
- In all our work and interventions, the potential for causing harm as an unintended, but nonetheless real, consequence must be considered from the outset.



«*Western aid workers traded food for sex from victims of disaster*»



## Exclusive: EU suspends funding to WHO programmes in Congo after sex scandal

BY STEPHANIE NEBEHAY  
28 OCTOBER 2021 AT 16:29 · 3-MIN READ

The European Commission has suspended funding to the World Health Organization's programmes in the Democratic Republic of Congo due to **concerns** over the U.N. agency's handling of the **sexual abuse scandal**.

An Oct. 7 letter from the Commission marked "**SENSITIVE**", seen by Reuters, informed the WHO of the immediate suspension of financing for five WHO programmes, including its Ebola and COVID-19 operations.

# Research ethics is basic in research

- Fairness & justice
- Research questions
- Design
- Methods & tools



# The same basic principles go

*Primum non nocere*

*First, Do No Harm*

*Do good*

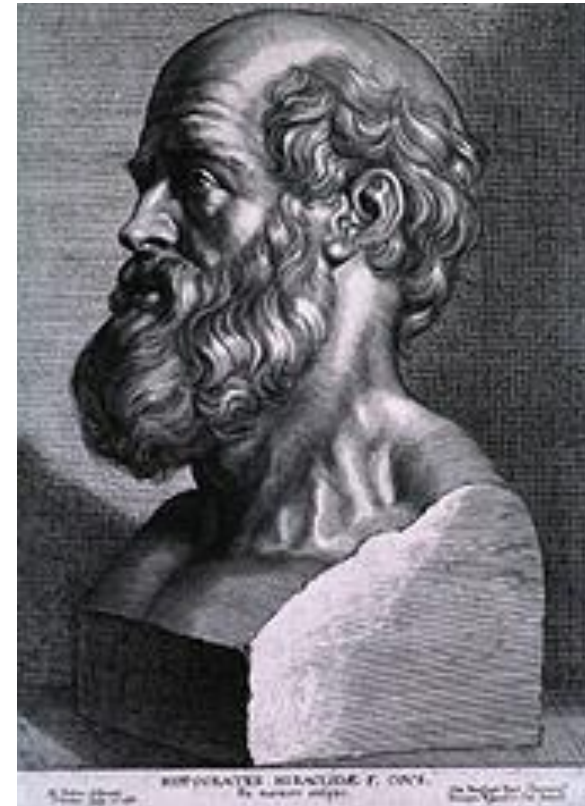
*Minimise harm*

*Justice*

*Fairness*

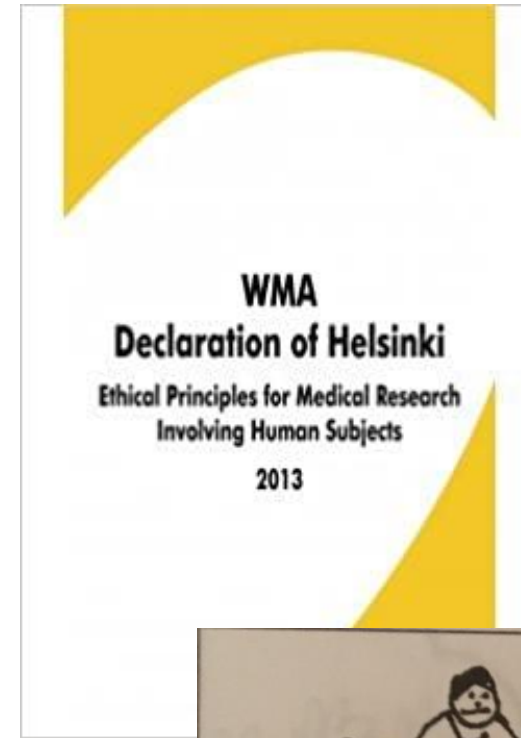
*Dignity*

*Autonomy*



# Respect for persons

- Autonomy
- Informed consent
- Confidentiality
- Anonymity
- 3rd party
- Voluntary & compensation
- Access to results and fruits



- Dissemination
- Authorship
- Coordination with existing systems
- Local vs int'l researchers
- Enduring institutions
- Capacity building
- Funding
- Accountability
- Environment, corruption

# Ethical Practice



## Principles and Guidelines for Research with Vulnerable Individuals and Families

### Notes: Investigative Research of Research Methods

The Journal of Caribbean Research is a peer-reviewed journal that publishes research on Caribbean research methods and research methods in research.

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### Highlights

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Volume 10, No. 1, 2019

# Minimum standard or best practice?

- Safety
- Do not impede relief and development efforts
- Legal and formal issues, incl ERB
- Co-operation
- Co-ordination
- Build on existing systems and resources
- Contingency planning





- Chiumento, A., Rahman, A., Frith, L., Snider, L., & Tol, W. A. (2017). Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates. *Globalization and health*, 13(1), 8.

**IASC**  
Inter-Agency Standing Committee  
IASC Reference Group for Mental Health and  
Psychosocial Support in Emergency Settings

**RECOMMENDATIONS FOR  
CONDUCTING ETHICAL  
MENTAL HEALTH  
AND PSYCHOSOCIAL  
RESEARCH IN  
EMERGENCY SETTINGS**



## DO'S AND DON'TS

DO	DON'T	FURTHER READING
Deliver immediate and direct benefits to communities.	Conduct research with no benefit to communities.	Research benefit: p. 14-15
Identify gaps in current knowledge and conduct research to fill these.	Duplicate previous research. <i>(note: not applicable to monitoring and evaluation measuring service delivery)</i>	Research purpose: p. 13
Carry out a thorough risk and benefit assessment, and develop risk management plans. Share with participants and staff.	Conduct research where risks and benefits are unknown.	Risk and benefit: p. 14
Consult with communities to identify fair compensation for research participation.	Randomly set compensation.	Compensation: p. 15
Share research knowledge <u>with</u> a range of audiences, including the participating community.	Disseminate in hard-to-reach formats.	Dissemination: p. 16–18
Ensure research plans consider these recommendations, other guidelines and legal standards, and is approved by relevant authorities prior to starting [where applicable].	Start research before obtaining all required approvals and support (i.e. ethical review [where applicable], community approval, informed consent etc).	Analysis of ethical issues: p. 18
Conduct research with meaningful participation of local stakeholders in research design, conduct and dissemination.	Conduct research <u>on</u> participants with no opportunities to contribute to design, conduct or dissemination.	Participation: p. 21
Identify research participants according to the scientific objectives of the study.	Allow gatekeepers to control access to participants.	Fair selection: p. 22–23
<u>Always</u> obtain informed consent before starting research.	Proceed with research if there are concerns about the reliability of consent.	Informed Consent: p. 24–26

DO	DON'T	FURTHER READING
Ensure participant protection needs take priority over the conduct of research, including referral pathways to accessible services and safety measures.	Conduct research without referral pathways and safety measures to respond to participant protection needs.	Protection: p. 32
Work to ensure the protection of participant anonymity, confidentiality and the right to privacy. Provide participants clear information about the limits to these.	Proceed with research when it may not be possible to maintain anonymity, confidentiality and the right to privacy, and the participant's security.	Confidentiality: p. 35
<u>All</u> members of staff must undergo training and supervision to ensure their competency.	Involve staff without training or supervision specific to the research being conducted.	Training the staff: p. 38
Have in place staff self-care, support and monitoring of competency to practice.	Continue with staff who are experiencing negative reactions.	Staff care: p. 43
Ensure that safety concerns are raised and responded to.	Conduct research where participant and / or staff safety cannot be reasonably managed.	Safety: p. 44
Maintain equity (treating all humans as equal) and impartiality (not taking sides or passing judgement).	Conduct research in emergencies due to perceived ease of access or prevalent conditions of interest alone.	Neutrality: p. 45
Be transparent about reasons for conducting research.	Allow outside interests to override ethical research practice.	Transparency: p. 46
Make sure research is well designed and avoid overgeneralizing research findings.	Conduct research where the methods are inappropriate and/or cannot be properly implemented.	Study design: p. 46–48

# Examples of dos and don'ts in research:

**Do** deliver immediate and direct benefits to communities.

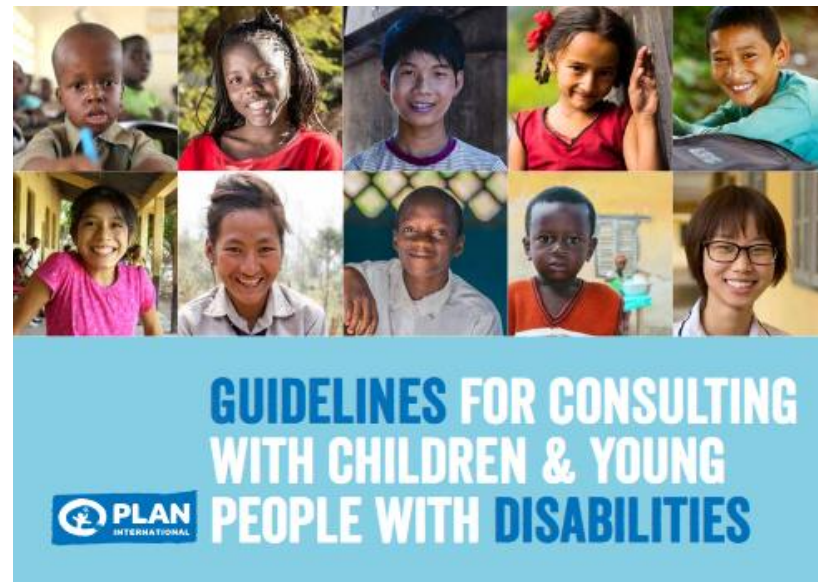
**Do not** Conduct research with no benefit to communities.

**Do** Identify gaps in current knowledge and conduct research to fill these.

**Do not** Duplicate previous research

[iasc recommendations for ethical mhpss research in emergency settings 0.pdf \(interagencystandingcommittee.org\)](https://interagencystandingcommittee.org/iasc_recommendations_for_ethical_mhpss_research_in_emergency_settings_0.pdf)





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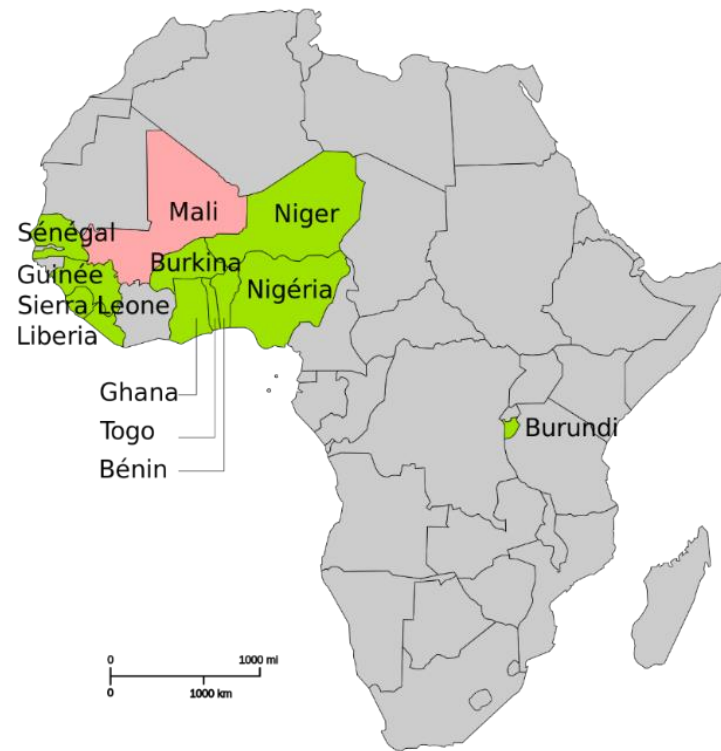
“If dignity is to have any meaning at all, it must honor the perspective of those affected...”

Consider the perspective of one Rwandan talking to writer Andrew Solomon:

*We had a lot of trouble with Western mental health workers who came here immediately after the genocide and we had to ask some of them to leave. They came and their practice did not involve being outside in the sun where you begin to feel better. There was no music or drumming to get your blood flowing again. There was no sense that everyone had taken the day off so that the entire community could come together to try to lift you up and bring you back to joy. There was no acknowledgement of the depression as something invasive and external that could actually be cast out again. Instead they would take people one at a time into these dingy little rooms and have them sit around for an hour or so and talk about bad things that had happened to them. We had to ask them to leave.*

Dyer, A. (2019). Global mental health: Ethical principles and practices. George Washington University Department of Psychiatry Grand Rounds, November 21, 2019

# Kielland, A. et al: Addressing Local Barriers to Inclusive Education for Children with a Disability in the Sahel. Child disability, education and social inclusion in rural Niger



## EXAMPLE:

### NORGLOBAL 2 **Child disability, education and social inclusion in rural Niger**

*Addressing Local Barriers to Inclusive Education for Children with a Disability in the Sahel*

#### *Partners:*

- Fafo, UiO, OsloMet
- London School of Hygiene and Tropical Medicine
- Laboratoire d'Etudes et de Recherche sur les Dynamiques Sociales et le Développement Local (LASDEL), University of Niger
- User organisations



# Vulnerable groups & sensitive topics

- Testing, examining and interviewing children with disabilities and their families
- Home visits

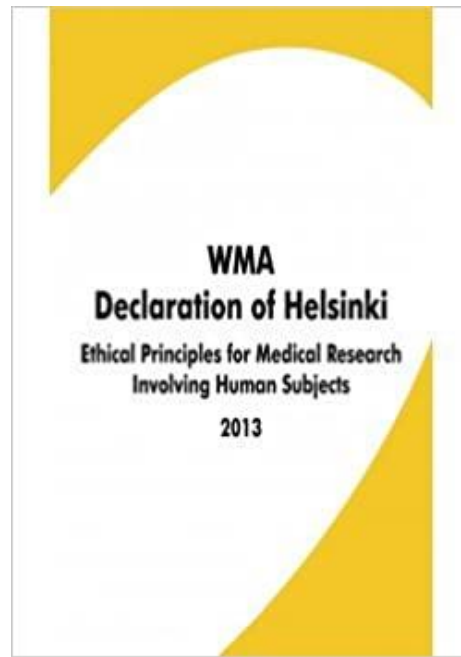




## **Ethics project: Research questions**

- How to do good and responsible research?
- What were the dilemmas?
- What solutions did we find?

# METHOD



# Results: Challenges

- Formal requirements of GDPR and permissions versus research ethics
- Design (e.g. topics, questions, method)
- Participation
- Safety, Respect, dignity, voluntary, compensation
- Informed consent: writte, oral, revisit
- Consult with commmunity



# Tools:

- Legal and formalities issues
- Ethical dilemmas
- Co-operation
- Capacity building



# Dilemmas & critical thinking, not simple answers

- “bad science makes for bad ethics” (Rosenthal 1999, p. 408).
- Basic principles of research ethics apply
- Power differences bring increased responsibilities
- What is your institution’s policy?
- How do you as researchers handle these dilemmas?
- How is research ethics reported and shared?

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