Strengthening Ethical Practice in Development and Humanitarian Research

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OUTLINE

- Background information
- Ethical Guidelines and Principles
- Ethical Issues in a Humanitarian Context
- Ethical Decisions in the Research Process
- Strengthening Ethics Architecture e.g. GOAL
- Specific Issues / Case Examples
- A Perspective of Ethical Virtues

Ethical Codes and Guidelines

a) Codes: Professional requirements not to be transgressed

b) Guidelines: Educative or Advisory Framework. No institutional sanction but intended as support for resolution of ethical dilemmas (e.g. DSAI Student Guidelines)

Responsibilities to:

- Those being studied
- Scholarship and Science
- The Public / Society
- Funders and Research Commissioners
- Researcher's Own and Host Governments

Ethical Principles

- Beneficence (Doing good)
- Non-malificence (Avoid doing harm)
- Protect the autonomy, wellbeing, safety, dignity of all research participants
  - Seek to ensure psychological well-being, even survival, of those being studied
  - Carefully and respectfully negotiate relationships
  - As objective as possible an analytical stance
  - No deception or misrepresentation
  - Obligation to use the results appropriately.
  - Principles extend to dissemination and reporting of findings and use of data

Ethical Issues in a Humanitarian Context

- Value
- Scientific Validity
- Subject Selection
- Harm-Benefit Ratio
- Independent Review
- Informed Consent
- Respect for Participants
- Source: O'Mathúna, D. (2015).

Ethical Issues through the Research Process

- Failure to consider the impact of research on culture, attitudes or values of the target populations
- Failure to engage appropriately those likely to be affected by the research in the research design
- Failure to ensure ongoing comprehensive informed consent
- Privacy harms including inappropriate use, transfer or storage of personal data – made more complex by the increasing use of digital data gathering technology
- Wrongs if research results are not shared with the community

Ethical Decision Making

- Justifiable 'Interventions'
- Researchers' Competence
- Research Quality and Design
- Minimising Harm, Maximising Benefit
- Selecting, Recruiting, Retaining and Releasing Participants
- Giving Information and Seeking Consent
- Monitoring Safety
- Privacy and Confidentiality (strategies)
- Dealing with Vulnerability
- Involving Subjects in Research
- Disseminating Findings
- Implications of internet and e-research

Ethical Scrutiny and Potential Harm - MSF

Ethical scrutiny is proportionate to potential harm of research - increases along a continuum (MSF):

- Initial assessment of needs; monitoring of interventions
- Retrospective/secondary analysis of routinely collected data
- Morbidity, mortality, nutrition surveys
- Operational research: evaluation of interventions
- Testing of new technology ie. Laboratory test
- Clinical trial testing new drug, vaccine, surgical procedure.

Strengthening Ethics Architecture

E.g: GOAL: Since 2014 GOAL has Strengthened it's Ethics Architecture

- Development of three year Operational Research Strategy (2014-2017)
- Establishment of an in-house Research Oversight Committee (2014) to review/consider and recommend operational research to GOAL's Senior Management Team
- Development of Guidelines on Operational Research for Ebola (2014) and research proposal request template. In line with this GOAL only considered operational research which had the approval of both the Sierra Leone National Ethics and Scientific Committee and one other internationally recognised Independent Review Board
- Data Sharing Agreement template/procedures (2015) to guide on release of anonymised data for secondary analysis (2015)
- Data Protection Working Group (2017) to guide on the implementation of the Generalised Data Protection Regulation which comes into force in 2018

Richardson, Johnston and Draper (2017) *A Systematic Review of Ebola Treatment Trials to Assess the Extent to which they Adhere to Ethical Guidelines.*

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0168975

teria nber	WHO	Emanuel et al.	MSF
1	Scientific design and conduct of the study	Scientific validity	• What is the research question? • Why is it important? • How is the methodology and proposed analysis appropriate given the research question(s)?
2	Risks and potential benefits	Favourable risk-benefit ratio	• What are the anticipated harms and benefits?
3	Protection of research participants' privacy and confidentiality	Respect for participants	• How do you plan to protect confidentiality? • How do you plan to access, store and distribute collected biological material? • What will happen when the research is either st or is complete? • How will the findings be disseminated? • How will the findings be implemented?
4	Informed consent process	Informed consent	• What are your plans for obtaining consent?
5	Community considerations	Collaborative partnership, social value	• What is the context in which the research will b conducted? • How has this influenced the research design? • Are there any other parties involved in the rese • What potential interests of these parties might with MSF's mission and values?
6	Selection of study population and recruitment of research participants	Fair participant selection	
7	Inducements, financial benefits and financial costs		
8		Independent review	
9			Are all relevant resources for the research secur
10			Have the research staff the relevant training and protection?

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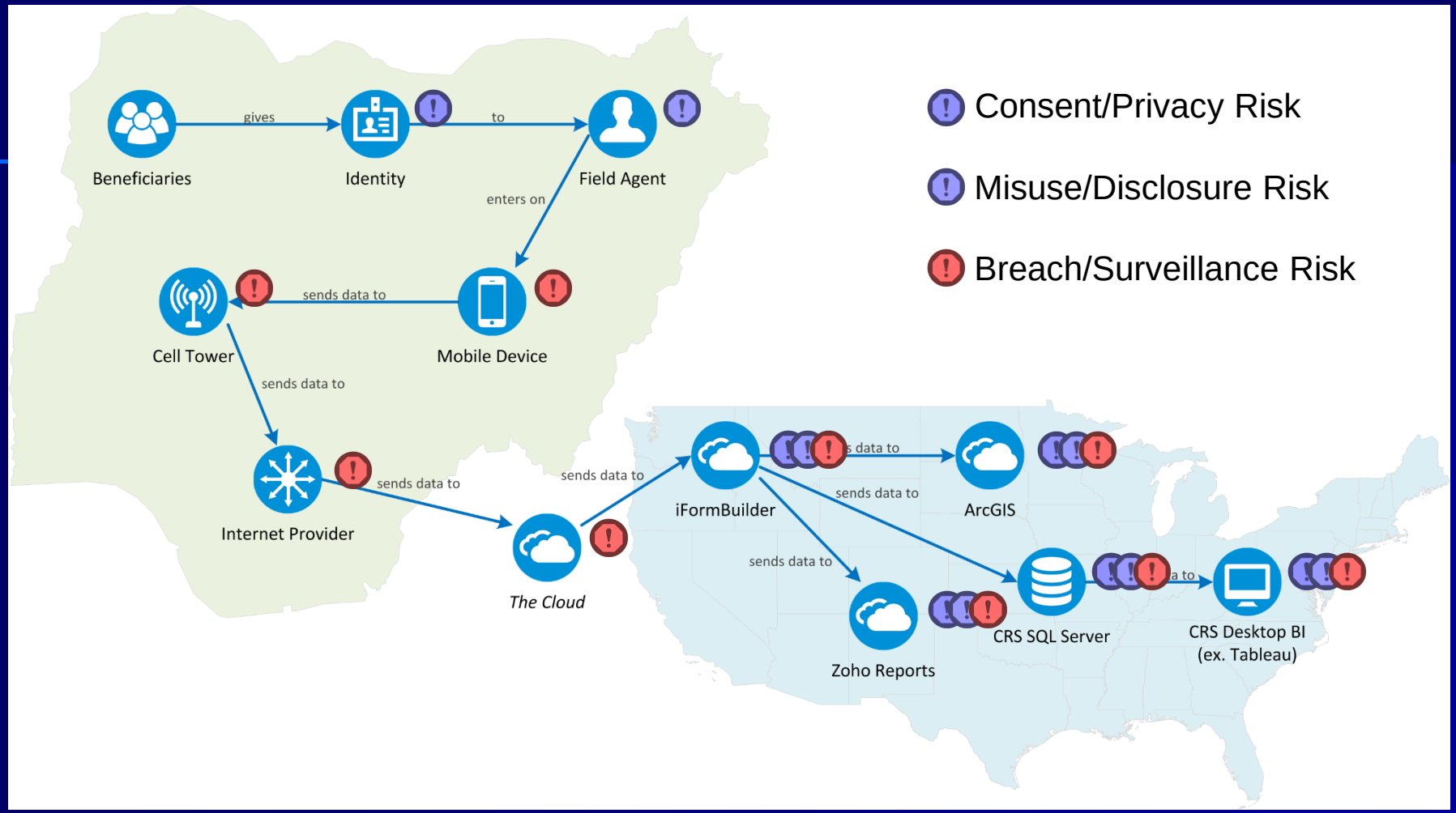
10 Criteria established by authors

- These ten criteria are:
- Appropriate scientific design, conduct and validity
- Favourable risk-benefit ratio
- Protection of research participants' privacy and confidentiality
- Appropriate informed consent process
- Collaborative partnership between researchers and community
- Fair participant recruitment and selection
- Inducements, financial benefits and costs
- Independent review
- Resources for the research
- Protection and training of research staff

RISKS AROUND SAFEGUARDING DATA:



Ethical research

From design to publication

Case study: Post-genocide Rwanda

The Research:
Investigating Childhood Adversity in Post-genocide Rwanda

- Northwestern Rwanda
- 16 months' ethnographic fieldwork
- Community-based, comparative approach (two communities)
- Children, young people and their families
- NGO representatives, local authorities and other state representatives

Case study: Post-genocide Rwanda

The context

- The 1994 genocide against the Tutsi
- Crisis in the humanitarian sector - lack of reflection
- Legacy of genocide on politics and social landscape
- While peaceful, political tension and fear persist
- Ethnicity difficult topic
- Tensions especially strong in northwestern Rwanda following the infiltration war 1998-2000

Ongoing ethical dilemmas

Physical safety:

- Frequent political harassment and imprisonment of 'dissenters'
- Frequent military and police patrols in northwestern villages
- Dangerous to speak out against the government
- Dangerous to speak of the infiltration war
- People considered Hutu especially vulnerable to surveillance

=> Could be dangerous to speak to a researcher

Psychological safety:

- Most participants had experienced either the genocide or the infiltration war
- Most participants had undergone periods of voluntary or forced migration and displacement
- Many female participants had been victims of sexual violence
- Many participants had lost many, if not all, family members
- Hutu people's suffering nationally unacknowledged

=> Huge trauma and risk of retraumatisation

Ongoing ethical dilemmas

Informed consent:

- People may not be aware of the social, political and psychological risks of participation
- In a context of poverty, participants may expect some financial or other benefit from involvement in research (in particular when associated with NGOs)
- People's desire/willingness to participate can change over time
- In the case of families or communities, who gives consent?
  - Different generations in a household/family may disagree about participation
  - Different individuals within a community may disagree about a community's participation
- Written consent not always the most appropriate
  - In Rwanda, written documents considered 'contracts' and hold immense social value (i.e. morally and socially difficult to reverse).
  - Written documents also associated with political bureaucracy, which people fear contradicting.

Measures taken I

1. **Employed a psychologist as interpreter and research assistant**
   - From the general area but not known to research participants
   - Aware of local and national tensions
   - Trained in counselling so could ensure potential traumatic flashbacks or psychological suffering emerging in conversations could be appropriately handled
   - Of Hutu origin so put (marginalised) Hutu participants at ease

2. **Collaborated with local authorities**
   - Gained their trust so they did not feel the need to oversee the research
   - Understood that political topics were not explored
   - Viewed by villagers as a way to communicate their problems to the local authorities

Measures taken II

3. **Data safety**
   - Ensured high security around my data (encrypted or anonymised all field notes, backups held outside the country, offline)
   - Never shared photos of area or participants
   - Did not share political findings with anyone inside the country
   - Area and participants completely anonymised and not mentioned in any publications ('northwestern' is the only regional indication)
   - Some locals not participating in the research used phones to take photos; approached and asked to delete the photos if any local participants were captured in the photo.

4. **Continuously sought informed consent throughout research**
   - People who originally agreed became uncomfortable and I reduced my interaction with them
   - People who originally refused to participate later wanted to participate
   - Found way to respect different family members' wish to participate/not participate by attending to and respecting familial 'politics of knowledge'

Measures taken III

5. Choice of methodology

- continuously reviewed appropriateness of chosen methods
- included participants in choice and design of methods
- different communities different preferences for methods

6. Analysis and dissemination

- Shared (non-political) findings with local authorities and at local conferences, meetings etc.
- Continuously summarised my research progress and findings with all participants to form new questions and discussions
- Reported findings to local NGOs while in the field
- Summaries and briefs to be written to NGOs operating in Rwanda or similar contexts
- Frequently tested my analysis with research participants and interpreter
- Ongoing consultation with many participants

Ethical Virtues: Individual and Institutional

- Researchers must think about and respond to ethical issues throughout a research project
- An ethical approval process AND everyday ethical decisions
  - Ethical approval AND ethical conduct
- Ethical codes, guidelines and principles
- But also personal characteristics and attributes that strongly impact ethical behaviour: honesty, faithfulness, respect
- Clear and careful ethical thinking: intelligent, informed, conscientious, compassionate, responsible investigators

Resources

- Declaration of Helsinki
- Nuremberg Code
- Belmont Report
- Dóchas Code and Guidelines
- DSAI Guidelines for Ethical Fieldwork Overseas
- Association for Research Ethics

Resources

- O'Mathuna, D. (2015). *Research Ethics in Humanitarian Emergencies*
- Richardson, Johnston and Draper (2017) *A Systematic Review of Ebola Treatment Trials to Assess the Extent to which they Adhere to Ethical Guidelines.* http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0168975
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