

The Role of Beneficence in Humanitarian Research

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Beneficence: Definition

- A concept in research ethics which states that researchers should have the considered possible or potential benefits to the research participant as a goal of any research study
- Respect for Persons/Autonomy
- Justice
- Non maleficence



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The Evidence for Beneficence

- “While the baseline of ‘do no harm’ is recognized as an important starting point, there is a growing sense that research into human suffering ought only to be justifiable if it contributes to the ending of that suffering.”¹
- “I feel bad just leaving there again without leaving them anything or just.. Couldn’t do a lot for them”²
- “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”³



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Beneficence in Humanitarian Research: An opportunity

- Direct Beneficence

- Indirect Beneficence



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Direct Beneficence

- Compensation
 - Cash based
 - Alternatives
- Access to Services
- Incentives vs compensation



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Indirect Beneficence

- Programs
- Advocacy
- Policy



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Misapprehension and False Expectations

- Although the refugee in each instance provides information willingly, such willingness appears to be based on a misapprehension of the research process.²
- These views indicate that the purposes of research, possible outcomes, the steps that will be taken by researchers to protect participants and, indeed, the longer-term moral relationship between researchers and researched have all been seriously misunderstood.²



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Potential Benefits of Beneficence

- Dignity for Research Participants
- Utilising an opportunity for assistance
- Improved relationship and trust with communities
- A reduction of research fatigue amongst participants



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Potential Consequences of Beneficence

- Social Desirability Bias
- Coercion
- Lack of Justice (example of resettlement)



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Case Study 1: Participatory Action Research

- Participatory Action Research (UNSW)
- UNHCR commissioned study to do qualitative interviews with survivors of sexual violence after a disaster
- Used a Participatory Action Research Method to conduct human rights and advocacy training with the final product being the women telling their stories in their own words



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Case Study 2: The Dharana Project

- A yoga and psychoeducation project to teach coping and resilience to unaccompanied refugee children who have experienced trauma
- Program is open to all, but only those who have consented will have the questionnaires and their data used



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Case Study 3: RCT during a famine

- Randomised Controlled Trial of supplement (RTUF) vs the normal standard of care supplement during a famine
- Consider
 - Justice in Beneficence
 - Non maleficence



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The Challenge for Researchers

- Funding
- Ethics Review Board
- Time and Resource heavy
- Knowledge Base and Experience
- Cultivating trusting relationships with the community
- Lack of research capacity within vulnerable communities



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Tool for assessment of Beneficence

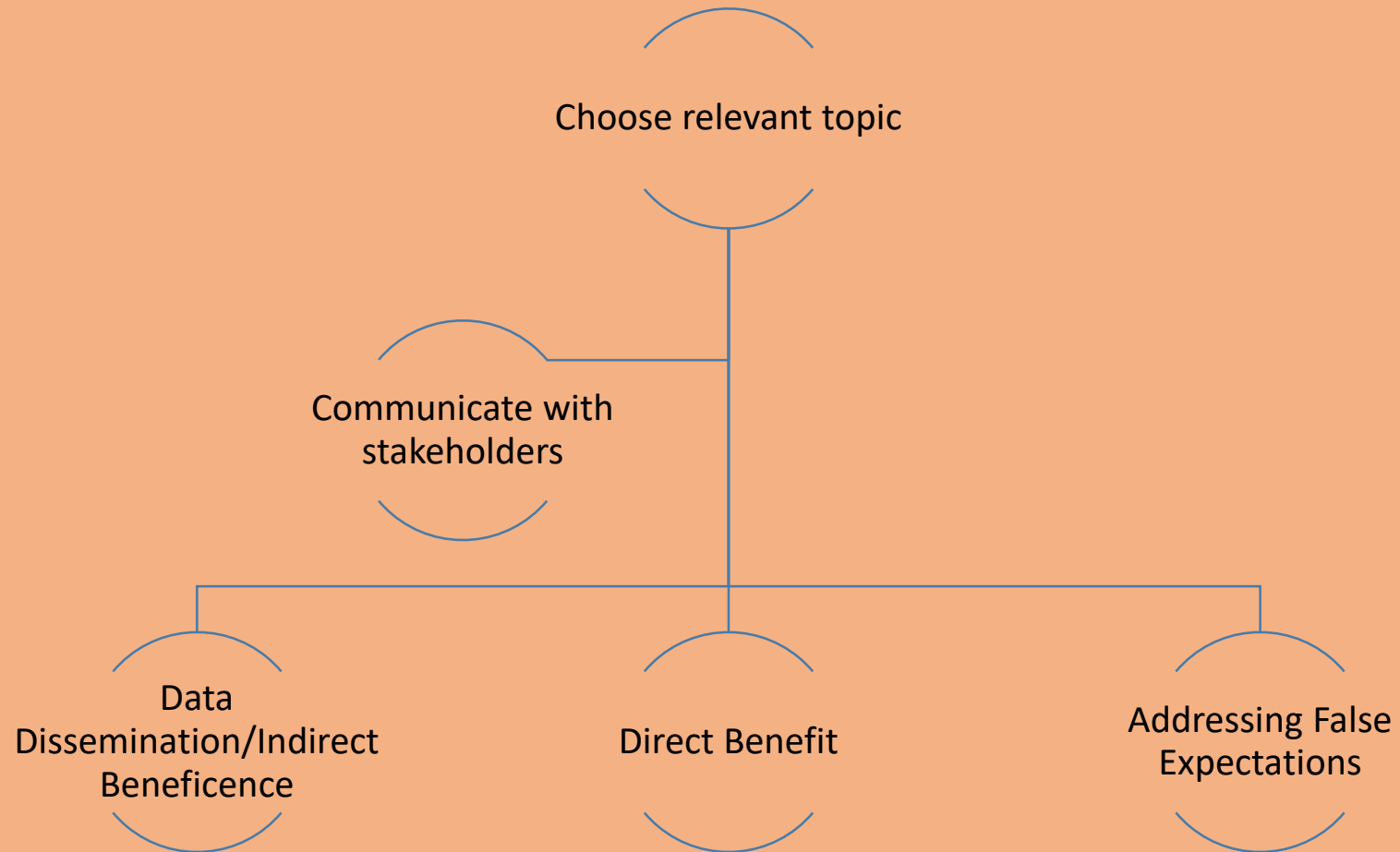
How to derive the appropriate, non-coercive, ethical benefit for each unique project and each population.

Qualitative interviews with researchers and previous study participants in various contexts and populations to understand

- (1) Positive and negative consequences of beneficence in research
- (2) Factors that should be considered in choosing form of beneficence
- (3) The place of beneficence on the research planning timeline.



Tool for assessment of Beneficence



Data Dissemination/Indirect Beneficence

- Who owns the data?
- Who does the data need to be disseminated to?
- Who are the NGOs in the area that have programs for the study population that could benefit from the information you collect?
- Does your study relate to any policy?
- What is the literacy level of the population? What is the best way to share the information you have collected?
- Would the information collected be risky to share to any of the stakeholders?
How will you manage this?



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Direct Benefit

- How much time are you asking from each participant?
- How is taking this time from the participant affecting their daily life?
- How would be the best way to compensate for this time and effort given to you by the participant (e.g. transport costs, incentives)?
- Is the incentive/compensation you are providing too much? Could it coerce the participant into the study?



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False Expectations

- Who is your research team made up of? Do any of the people hold important positions in the community or NGOs/International Organisations?
- What are the perceptions of the population to researchers?
- How much previous research has been done? And to what effect?



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How do we enhance beneficence in our projects?

- Finding an appropriate form of direct beneficence
- Clear and elaborate informed consent process
- Maximising indirect benefit through advocacy (including a data dissemination strategy)



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Conclusion: Recommendations for Researchers

- Think about the four ethical principles from the beginning
- Give yourself time to do the research project – it is hard to do ethical research quickly!
- Budget for compensation/beneficence
- Engage a bioethicist early, to ensure your review with the ERB goes smoothly and doesn't take too much time
- Speak to experienced researchers
- Prepare an advocacy strategy



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