



HOW TO INVOLVE VULNERABLE GROUPS
IN FOCUS GROUPS AND INTERVIEWS

POCKET GUIDELINES FOR ETHICS

SARA BONATI, UNIVERSITÀ DEGLI STUDI DI FIRENZE
OLGA NARDINI, UNIVERSITÀ DEGLI STUDI DI FIRENZE
FRANCESCO GRAZIANI, SAVE THE CHILDREN ITALY

JULY 2021



POCKET GUIDELINES FOR ETHICS

These guidelines can be used to engage vulnerable groups in research activities, as they aim to minimise stigmatisation



HUMAN DIGNITY

All humans should be respected, independently from age, gender, socio-economic conditions, ethnicity, sexual orientation, religion



VULNERABLE GROUPS

People whose susceptibility to the impacts of hazards is increased by physical, social, economic and environmental factors or processes (see UNDRR Glossary)

BEFORE RESEARCH

PLAN WELL WHAT IS THE PURPOSE OF YOUR RESEARCH

Identify the **risks** and the (positive and negative) **potential impacts** of your research



PLAN THE DISCUSSION

- Define instructions **easy to understand**
- **Test** the questions of discussion to make sure they can be understood
- Plan **regular breaks**
- If **persons with hearing impairments** are engaged, ensure to have sign language or a device support



PROVIDE INFORMATION TO RESEARCH PARTICIPANTS ABOUT THE PURPOSES OF THE RESEARCH

Prepare the **information sheet** and the **informed consent** modules.

- Use **accessible language**
- Be clear about the **data** you plan to collect and where/how long you will store it
- Give the opportunity to **make questions**



ADEQUATELY MANAGE AUDIO DATA

- Inform participants about the **recording device** you use and where/how long you plan to store the audio files
- Inform participants if you intend to use an **automated transcription method**

For in person events

SELECT THE ENVIRONMENT WHERE THE RESEARCH TAKES PLACE

- Give the participants the possibility to **suggest a place**
- Evaluate and **prevent risks**
- Ensure the environment is accessible for people with **different backgrounds, abilities, ages**
- Ensure the space allows people to **feel safe and protected**
- Consider providing participants **water and snacks**



For online events

BE SURE THE PLATFORM IS ACCESSIBLE

- Send the **informed consent via e-mail** (and request a signed copy)
- If not possible, collect (and register) **oral consent**
- Provide an **electronic informed consent**



WHEN YOU PLAN TO INVOLVE VULNERABLE GROUPS...


- Can I avoid involving these people? Is there another way to obtain the same information? Is their participation essential for the success of the research?
- What is the potential impact of my research on them? Could I increase their vulnerability?
- How is my work useful for them? Who is the main beneficiary of the research?
- Have I adequately planned measures of mitigation to reduce my impact on their life?
- Have I adequately adapted the research to their capacities/abilities/sensitivities?
- How will my presence produce effects on their behaviour and perception of the future? Have I adopted adequate systems of assessment of research impacts, involving them in the evaluation process?

DURING RESEARCH


ENSURE GOOD COMMUNICATION AND ETHICAL PARTICIPATION

- 
- Present **yourself**, the **organisation** and the **objectives**
 - Ask **autorisation to take notes**
 - **Never pressure participants** into participating, leave them the time to answer and show respect in case someone does not answer
 - With participants with cognitive impairments, use **simple language**, asking support of caregivers
 - **Ensure breaks** to avoid distress (especially with people experienced fatigue and anxiety)
 - Inform that participants are **free to withdraw from activities** at any time (re-check at the start of each session that people want to participate)
 - Continue **monitoring the well-being** of participants
 - Develop **research content appropriately accessible** across different ages groups, abilities, ethics, languages


AVOID STIGMA AND PROMOTE INCLUSION

- Prevent possible situations of **power disparity** (don't bias answers)
 - Prevent **stigmatization** (organize warm-up moments, asking setting clear expectations and house rules that promote respect for diversity)
 - Always use **accessible and gender-sensitive language**
- 

AVOID STRESS AND RETROSPECTIVE TRAUMATISATION

- 
- Avoid activities that can **recall traumatic experiences** (e.g. situations connected to recent disasters)
 - In asking something about previous experiences of disaster, consider a strategy to mitigate the **risk of retraumatization**
 - Activities that recall traumatic events should be conducted by **specialized staff** (psychologists and psychotherapists)

FINAL TIPS

- Allow time for people to **ask their own questions** and explain again what happens with the collected data
 - **Do not make promises** about what comes next or people may receive
 - For the Focus Group: **debrief together** and write up any additional information as soon as possible so that it is not forgotten
- 

AFTER RESEARCH

PREUDONYMIZE DATA

- 1** Establish a **set of codes** to be used. Participants will be identified with these codes (e.g. replace the identifiers with number: ID1, ID2, etc.)
- 2** **Collect all the personal data** that can identify the participants in a first document and report their statement in a second document (where only the selected indication code will be used)
- 3** Store the key files (which link to the pseudonyms to the identifiers) in a **secure system**. Delete the list with the names of participants once data have been processed
- 4** **Pseudonomize** the data to share with the research partners



LEARN MORE:

- Bonati, S., Graziani, F. (2020). LINKS Ethics Requirement No.1. Deliverable 10.1 of LINKS: Strengthening links between technologies and society for European disaster resilience, funded by the European Union's Horizon 2020 Research and Innovation Programme (No. 883490). Retrieved from: <http://links-project.eu/deliverables/>
- Bonati, S., Morelli, S. (2020). LINKS Ethics and Societal Impact Strategy. Deliverable 1.5 of LINKS: Strengthening links between technologies and society for European disaster resilience, funded by the European Union's Horizon 2020 Research and Innovation Programme (No. 883490). Retrieved from: <http://links-project.eu/deliverables/>
- Hoffman, B., Hartley, K., Boone, R. (2005). Researching accessibility: guidelines for creating and refining digital learning materials. Technology Trends, Marshall Raskind, Dept. Editor 171-176
- Focus Group Discussion Guide Capturing Community Perspectives & Risk Communications: COVID-19, IOM. Retrieved from: https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/capturing_community_perspectives_risk_communications_-_covid-19.pdf



LINKS



This project has received funding from the European Union's Horizon 2020 Research & Innovation Programme under Grant Agreement No. 883490

<http://links-project.eu/>

