



HOW TO INVOLVE VULNERABLE GROUPS  
IN FOCUS GROUPS AND INTERVIEWS

# POCKET GUIDELINES FOR ETHICS



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# 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

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- 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**
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### AVOID STRESS AND RETROSPECTIVE TRAUMATISATION

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- 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
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## AFTER RESEARCH

### PSEUDONYMIZE 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:

1. 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/>
2. 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/>
3. 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
4. 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](https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/capturing_community_perspectives_risk_communications_-_covid-19.pdf)



# LINKS



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