Course material

Course:

Ethics in Emergencies

Video:

4b fairness in participant selection

Concepts (extracted from automatically generated subtitles):

Needs of such clinics. Identification of all potential research participants. Implementation researchers. Importance of vulnerability. Pregnant women. Health care. Research participation. Needs of such individuals. Study of strategies. Small remote clinics. Potential benefit. Community engagement. Such groups. Potential research participants. Form of vulnerability.



to video sequence search
(within Ethics in Emergencies.)



to video

CHAPTER 2B

Ethical considerations in planning implementation research in emergencies

Fairness

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notes

summary

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Fairness in participant selection



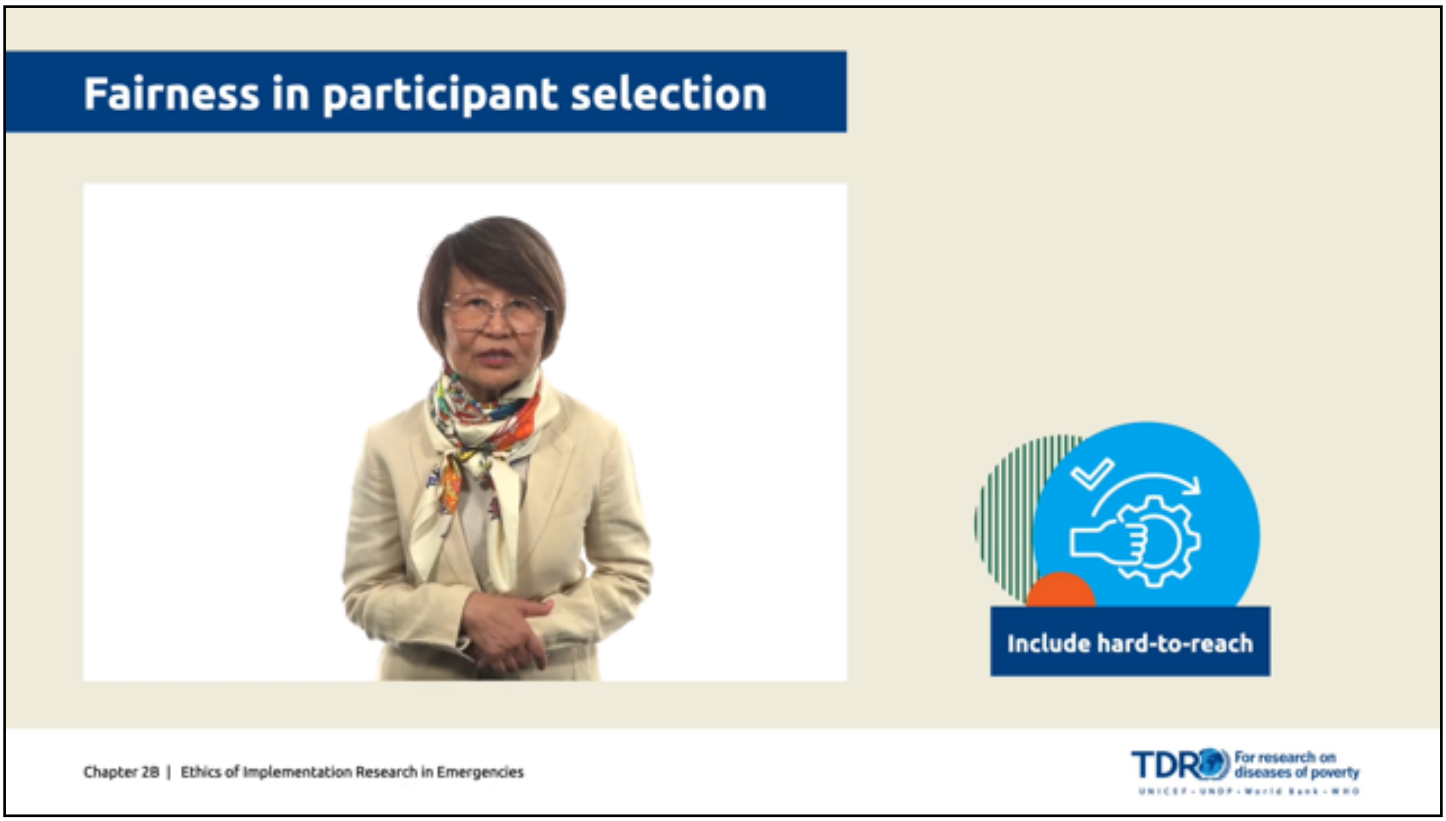
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Identification of all potential research participants is also important

notes

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for implementation researchers when considering the ethical principles of justice or fairness in research participation in an emergency. All potential research participants should have an equitable opportunity to participate in a study such that they may potentially benefit, but also to ensure meaningful representation of all relevant groups in a study. Researchers must

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0m 14s

Fairness in participant selection





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therefore plan how to include communities that may be hard to reach in an

notes

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0m 47s

Fairness in participant selection







emergency. Because this may be more challenging, it is even more

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0m 52s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics



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important to make additional provisions from the start to overcome any logistical hurdles and ensure the inclusion of groups that would otherwise be left out. If you consider the study of strategies to avoid staff burnout and

notes

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1m 1s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics



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internet access is erratic in some small remote clinics, these clinics should not be summarily excluded from the psychological support offered as a staff

notes

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1m 17s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use



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intervention. Researchers will need to develop a strategy, such as using mobile phones, to get around this barrier and ensure the clinic

notes

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1m 32s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use
- **Importance:**
  - Potential benefits to participants



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staff have an opportunity to participate. This is important not only

notes

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1m 48s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use
- **Importance:**
  - Potential benefits to participants
  - Meeting the needs of hard-to-reach participants

Community engagement is crucial



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for their potential benefit, but also to permit researchers to understand what a sustainable solution may need to look like if adopted, and scaled up to meet the needs of such clinics, identifying the resources needed to

notes

summary

1m 54s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use
- **Importance:**
  - Potential benefits to participants
  - Meeting the needs of hard-to-reach participants

Community engagement is crucial



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reach this ethics in the planning stage of implementation research in

notes

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2m 12s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use
- **Importance:**
  - Potential benefits to participants
  - Meeting the needs of hard-to-reach participants

Community engagement is crucial



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emergency requires careful and inclusive stakeholder and community engagement, which will be discussed in more depth in the next section, as well as ensuring

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summary

2m 13s

Hard-to-reach participants

- **Example:** Erratic internet access in small clinics
- **Possible strategy:** Mobile phone use
- **Importance:**
  - Potential benefits to participants
  - Meeting the needs of hard-to-reach participants

Community engagement is crucial



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adequate resources are in place for the researchers to be able to go the extra mile

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2m 36s



and include those who may be most difficult to reach. As we have just discussed, identifying those who may be hard to reach is

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important to ensure appropriate inclusiveness in research participation. Such groups may not only be physically hard to reach, but at times may

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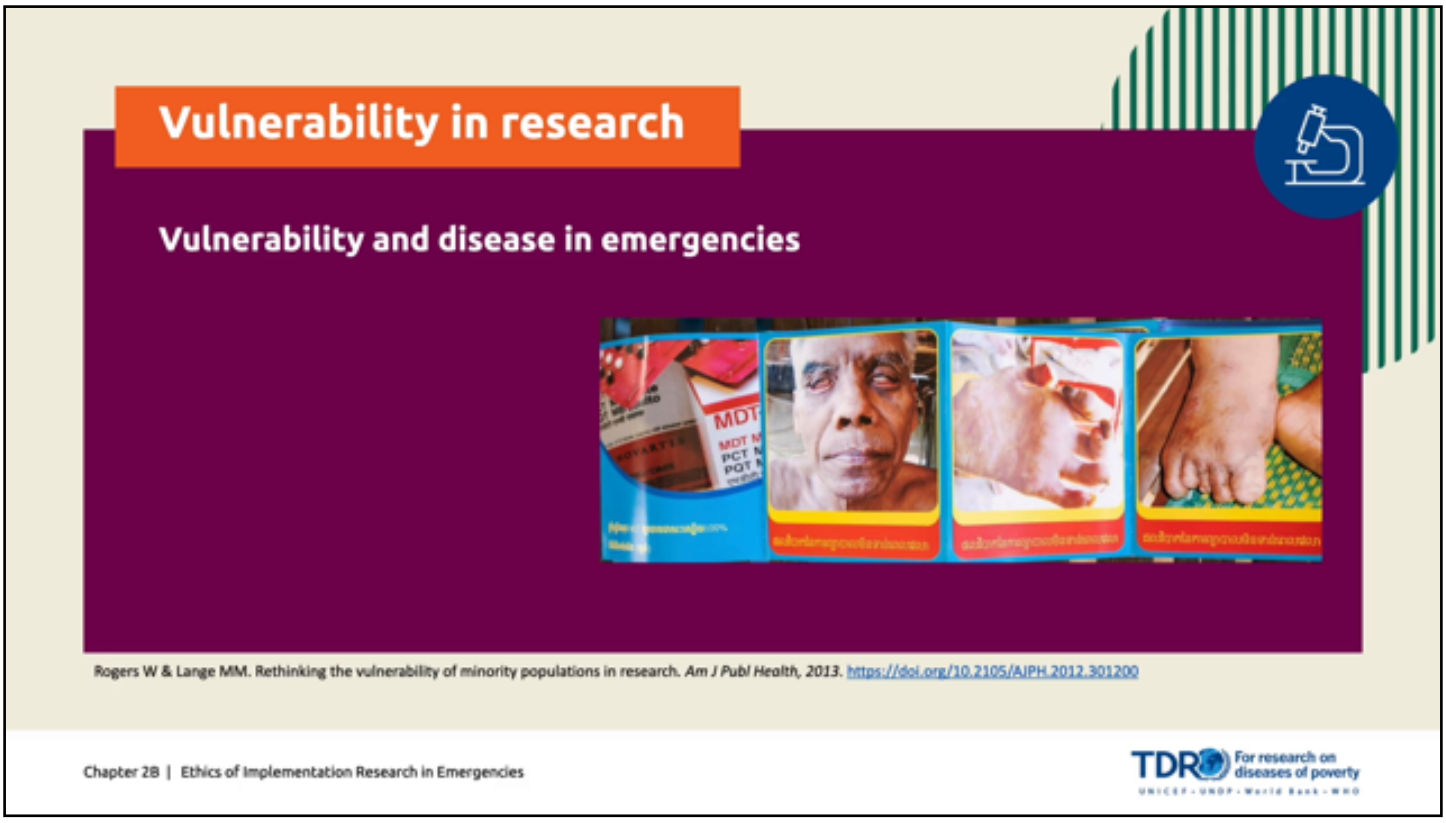


also be vulnerable to exclusion based on other factors such as stigma, discrimination, remoteness, language barriers,

notes

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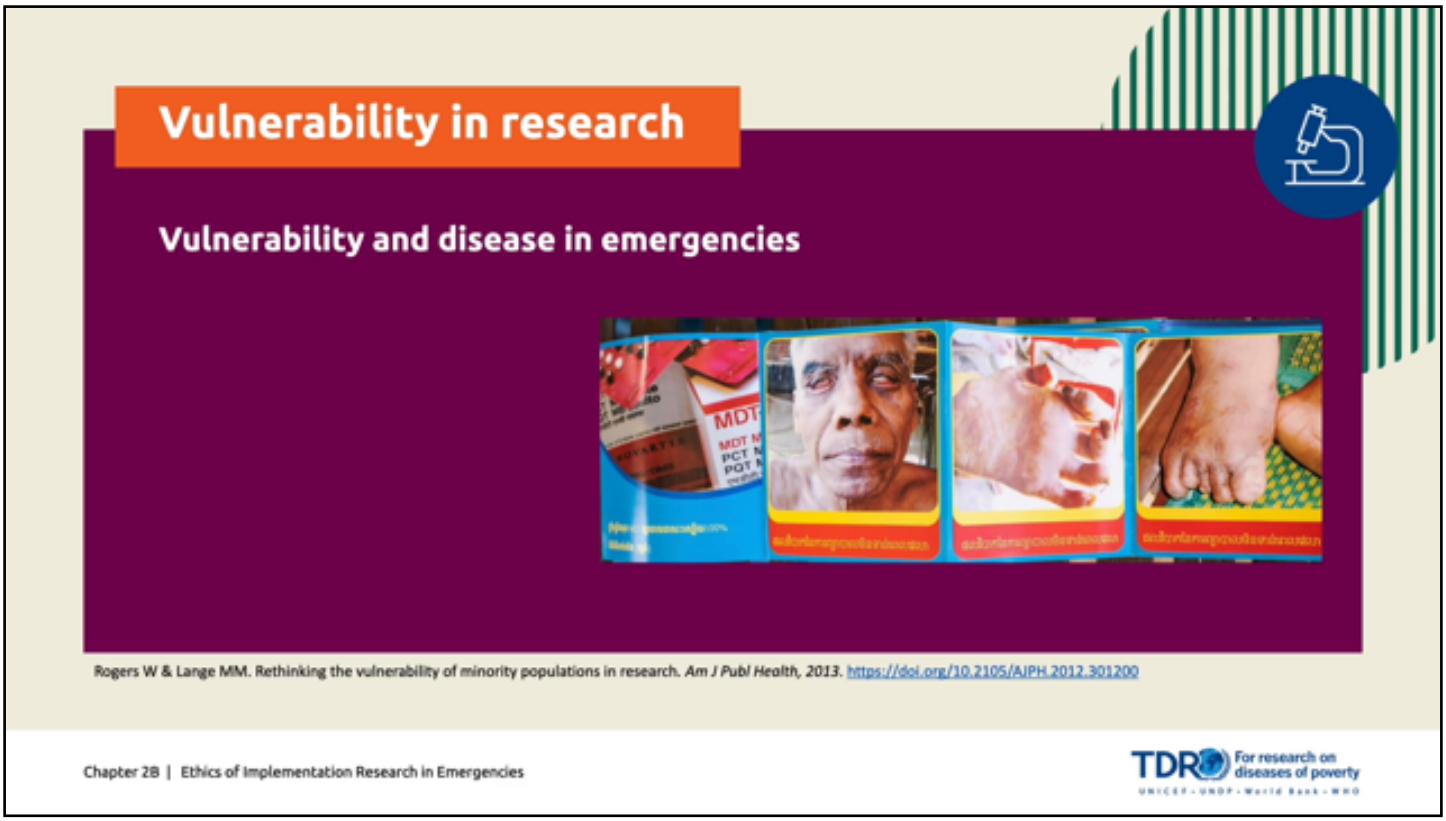


age and gender, among others. To highlight the importance of

notes

summary

3m 23s



vulnerability, let us consider a condition like leprosy. People

notes

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3m 25s

Vulnerability in research

Vulnerability and disease in emergencies

- Reduced mobility and resilience



Rogers W & Lange MM. Rethinking the vulnerability of minority populations in research. *Am J Publ Health, 2013*. https://doi.org/10.2105/AJPH.2012.301200

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living with disease cannot be forgotten in emergencies. Those severely affected may be disfigured and subjected to stigma, and their

notes

summary

3m 37s

Vulnerability in research

Vulnerability and disease in emergencies

- Reduced mobility and resilience



Rogers W & Lange MM. Rethinking the vulnerability of minority populations in research. *Am J Publ Health, 2013*. https://doi.org/10.2105/AJPH.2012.301200

mobility and resilience may be reduced under usual conditions

notes

summary

3m 48s



and maybe worsen in an emergency. Importantly, however, the disease will progress if they are not diagnosed or if their treatment is interrupted in addition to other needs that may increase as they do for everyone else. It is important, therefore, that the needs of such individuals are met even in emergencies. Strategies must therefore be developed to meet the needs of such communities. In turn, the leprosy community may be reluctant to accept new interventions, having been over researched and/or

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3m 50s



let down by studies in the past, and maybe afraid of further stigmatization. These factors must be considered.

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Vulnerability may therefore have multiple facets, which may be exacerbated in emergency as needs multiply, but solutions are limited. Vulnerability may also be augmented by fear, isolation,

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displacement, chaos, communication challenges, injury, and illness. All of these factors impact the autonomy of a research participant. Another form

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5m 20s



of vulnerability is important to keep in mind,

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summary

5m 32s



especially in emergencies when health systems may be severely disrupted. It is easy to imagine how research participation may be misinterpreted as health care. This concept is called therapeutic misconception.

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5m 38s

Therapeutic misconception



- Research seen as healthcare
- Exploitation of people in need
- Participation in the hope of obtaining better care

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This renders people vulnerable to exploitation in research as the hope of health

notes

summary

6m 1s



care may drive research participation. For example, research into an intervention to increase uptake of vaccine in pregnant women during antenatal care visits during an

notes

summary

6m 10s

Therapeutic misconception



- Research seen as healthcare
- Exploitation of people in need
- Participation in the hope of obtaining better care

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outbreak may be mistaken for antenatal care itself, and may drive women to accept vaccination in the hope of getting better care, even when they may

notes

summary

6m 22s



otherwise have been hesitant. To mitigate such misunderstandings, researchers need to ensure they are very transparent about their study, its place in relation to the available healthcare, their roles

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summary

6m 37s



and their capacities. This is best achieved through careful community engagement.

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Vulnerability and justice



The ethical implications when additional health care needs arise during research is

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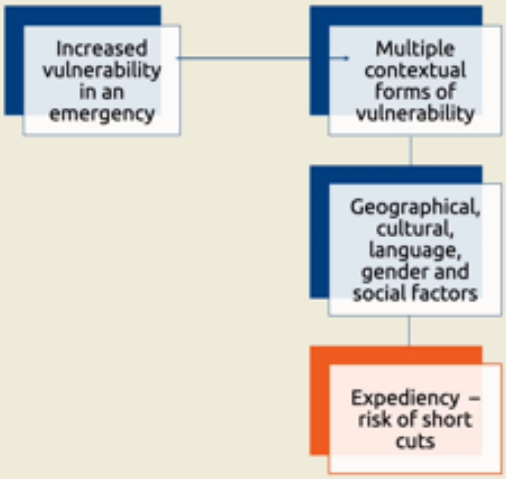
discussed in a later chapter three. Caution must be taken to not overlook multiple contextual forms of vulnerability, including geographical, cultural, language, gender, and social factors.

notes

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Vulnerability and justice



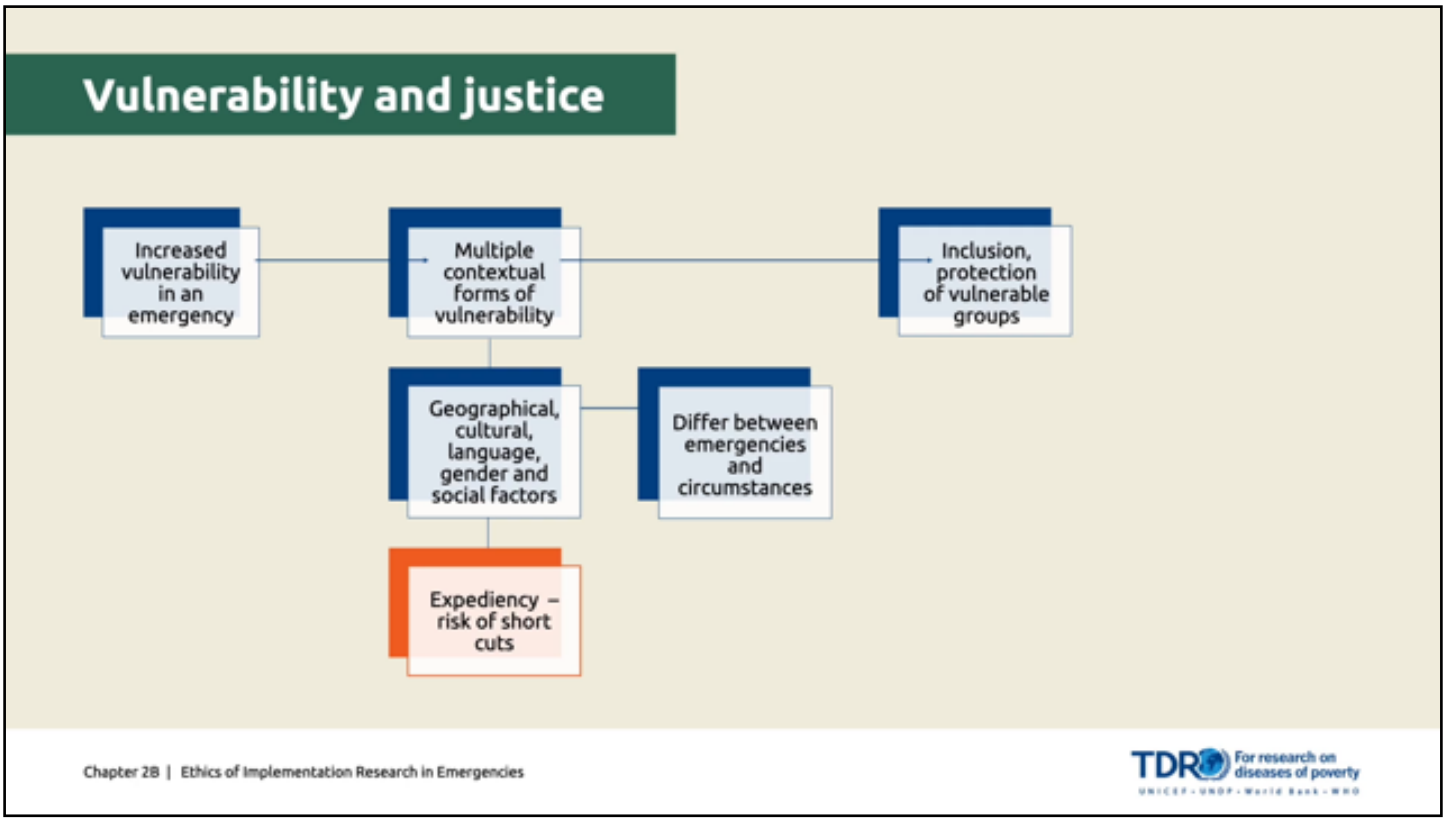
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Urgency and expediency may tempt researchers to take shortcuts,

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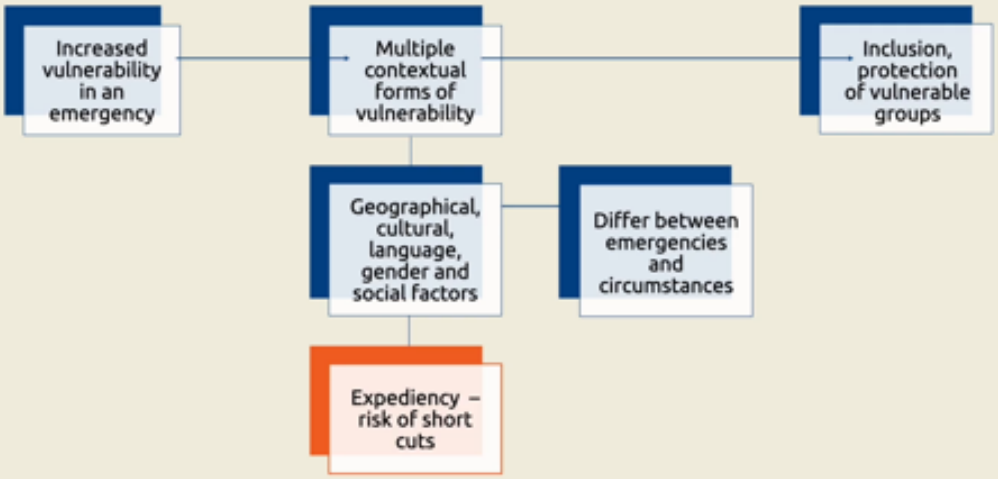
especially in implementation research conducted in complex emergencies. It is very important, therefore, that the most vulnerable are not exploited, but are also not left behind.

notes

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Vulnerability and justice



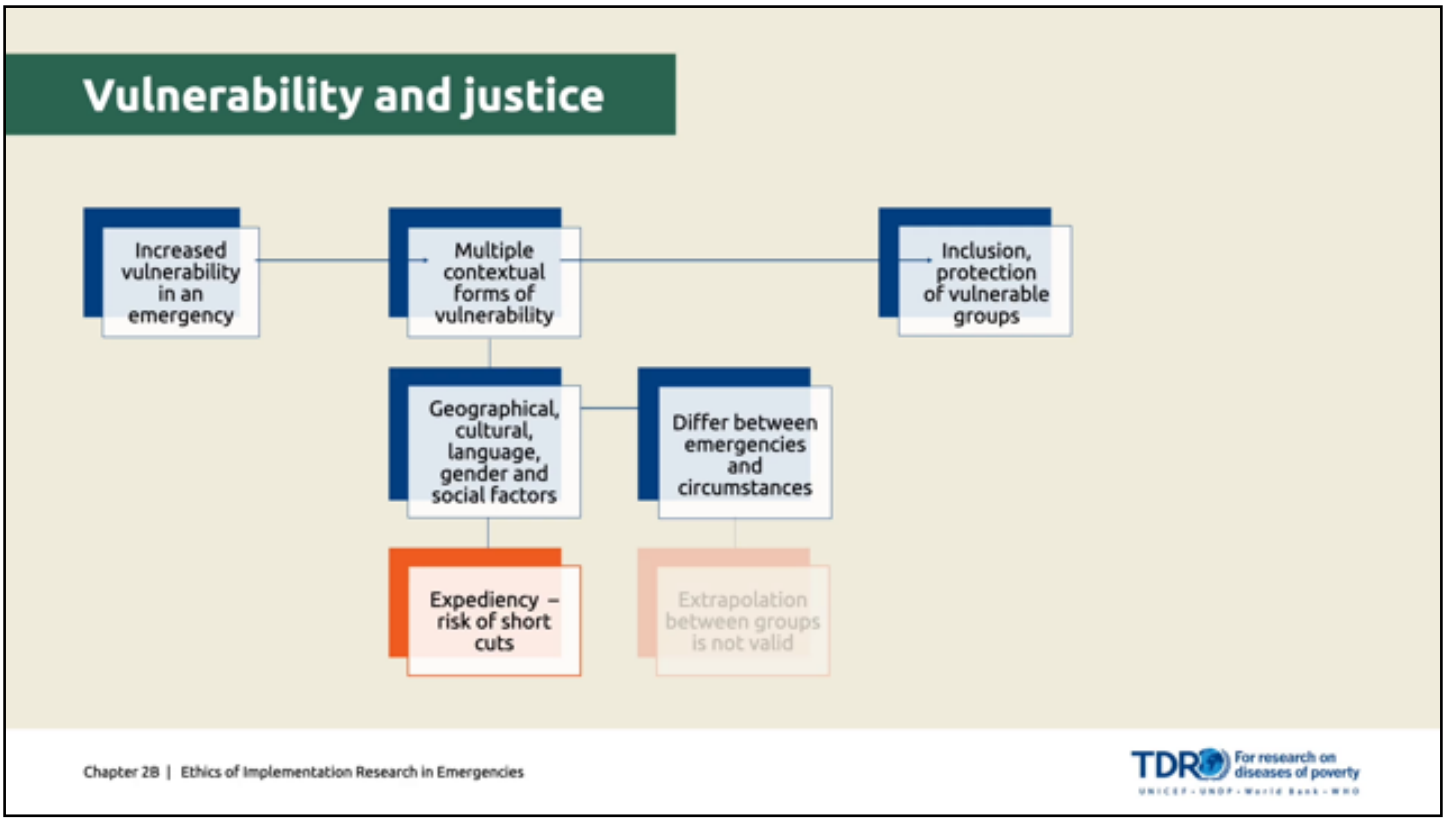
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Particular vulnerabilities may differ between emergencies and contexts

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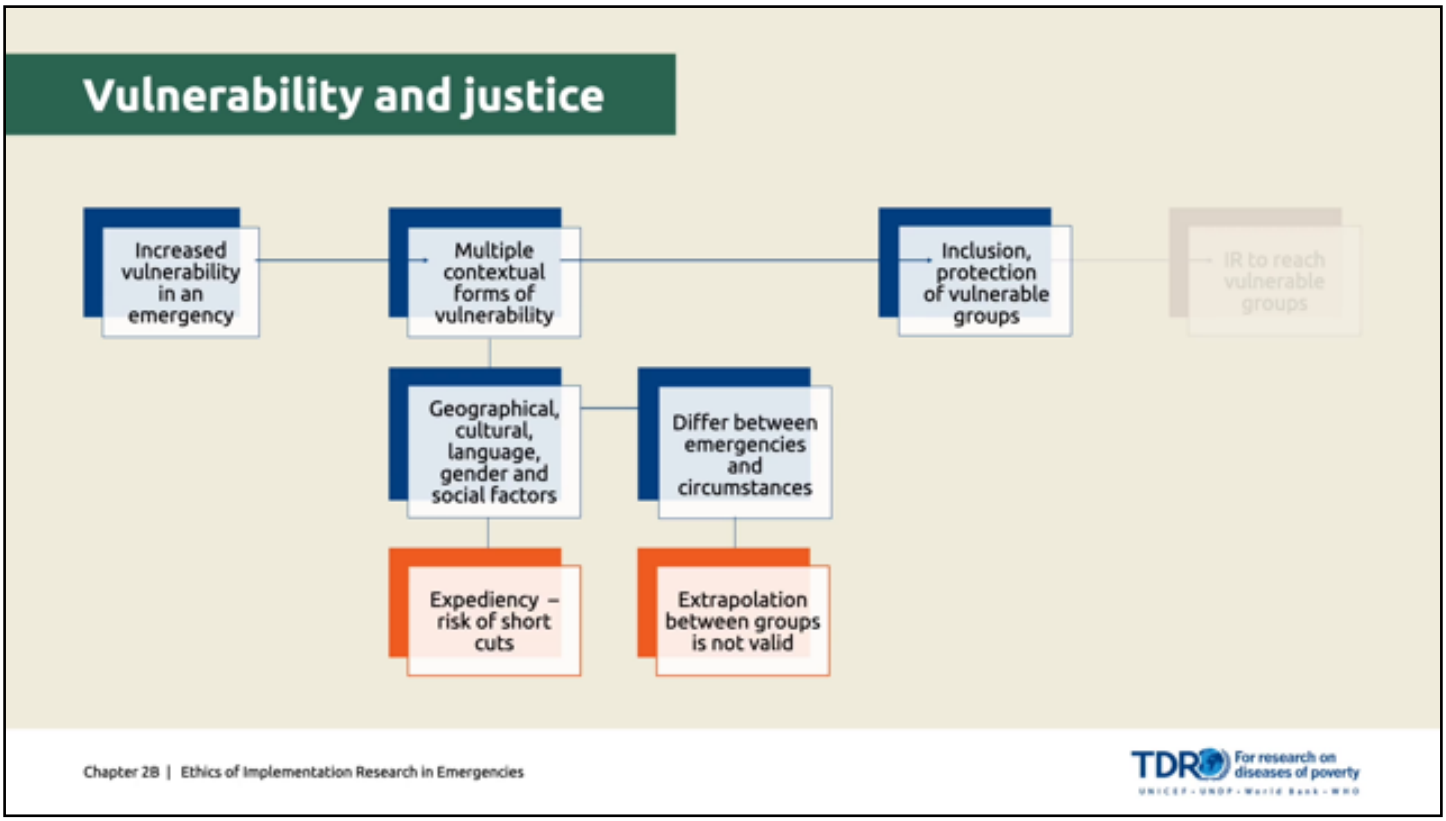


and may impact an individual or community's vulnerability or resilience differently. For example, pregnant women were at the highest risk of death during the Ebola crisis, the elderly may be the least able to flee in a natural or manmade disaster. Risk communication in an emergency may have cultural or language implications.

notes

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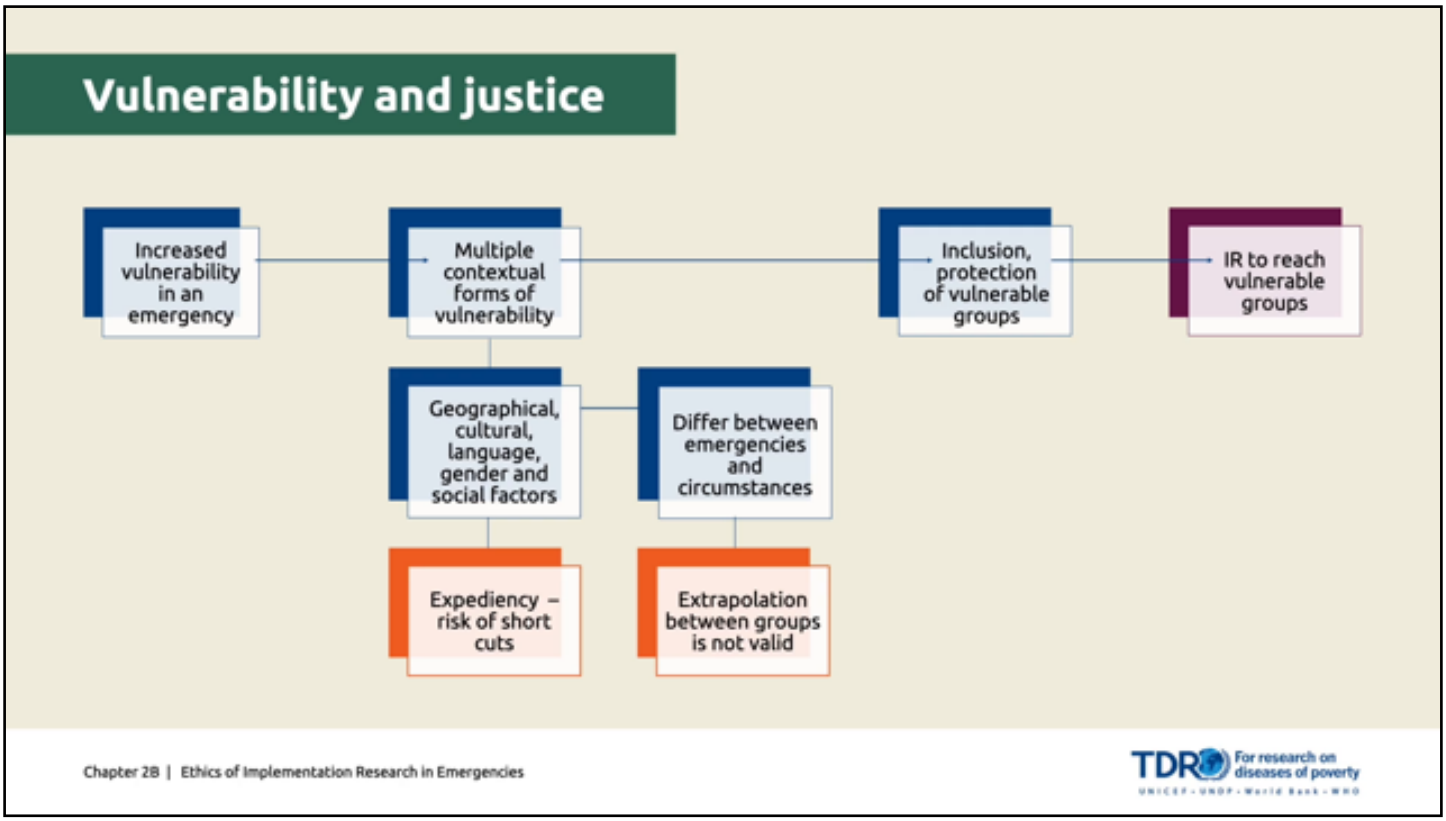


Simple extrapolation of research findings from one group or context to another would not be valid. As

notes

summary

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such, implementation research may be required to understand how best

notes

summary

8m 53s



to reach or meet the needs of the most vulnerable groups, which will be more urgent and highly contextual in emergencies. This will be best achieved by careful and inclusive stakeholder and community engagement.

notes

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