Course material

Course:

Ethics in Emergencies

Video:

5a Ethical norms guiding community engagement

Concepts (extracted from automatically generated subtitles):

Appropriate community. Careful planning of implementation research. Ethical imperatives. Stakeholder engagement. Required level of communication. Example of rabies vaccination. Better position. Ethical conduct of implementation research. Large refugee community. Fundamental goal of building trust. Importance of community. Most fundamental ethical norm. Non-obvious risks. Priority need of the community. Effective community.



to video sequence search
(within Ethics in Emergencies.)



to video

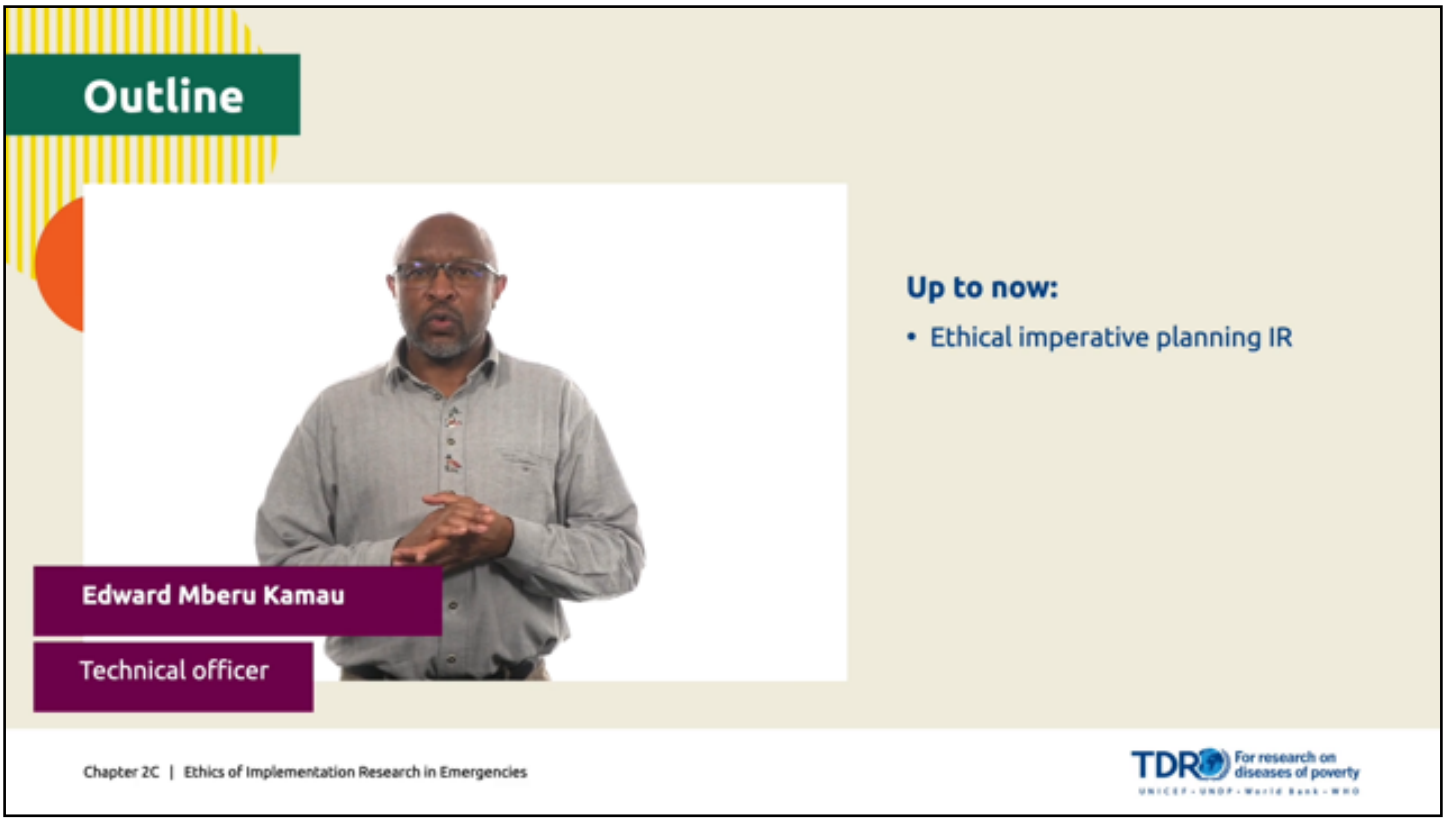


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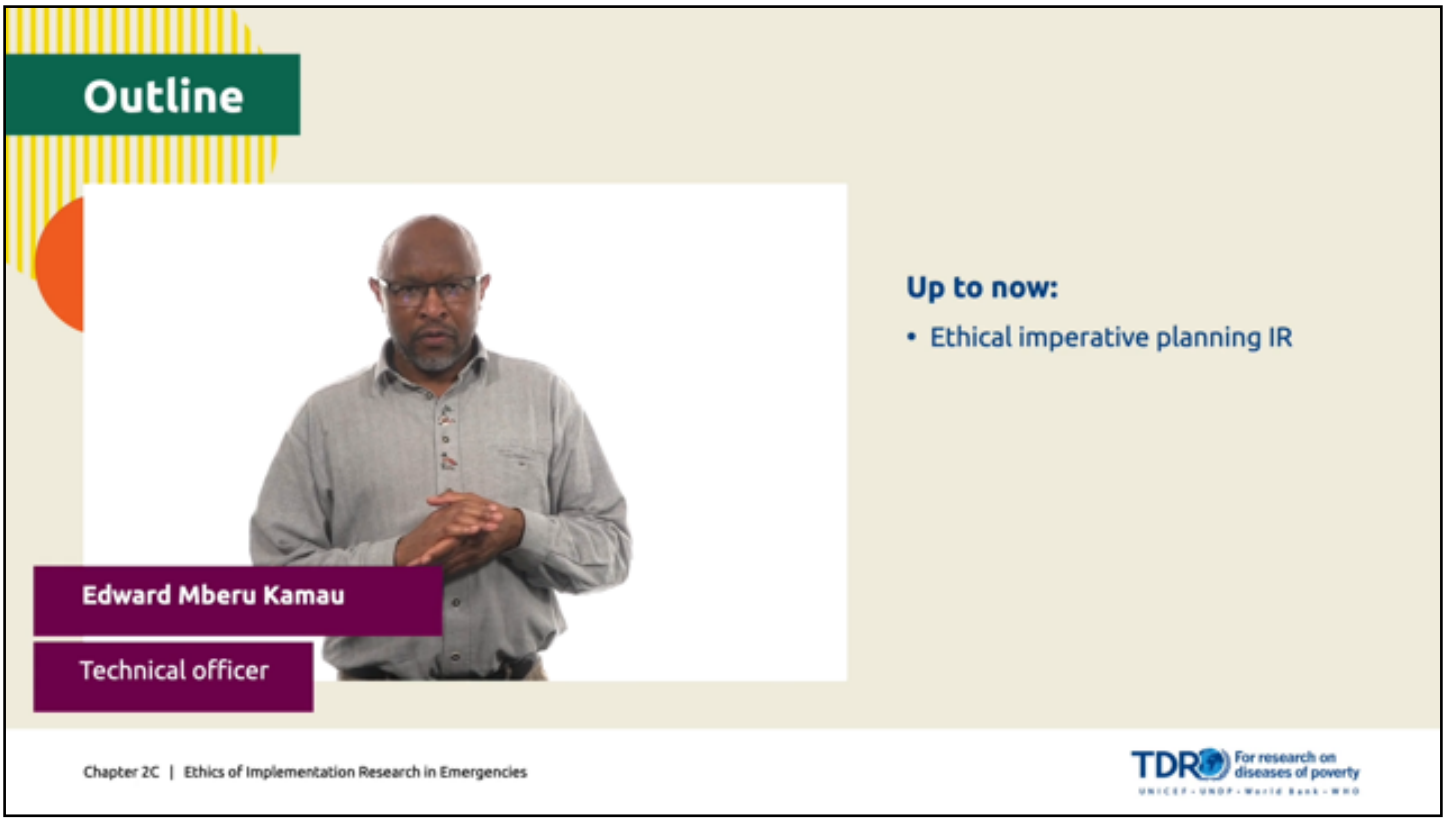


My name is Edward Mberu, a technical officer working for the Special Program for Training and Research, also known as TDR, based at the WHO headquarters in Geneva. Now that we have reviewed the ethical imperatives related to

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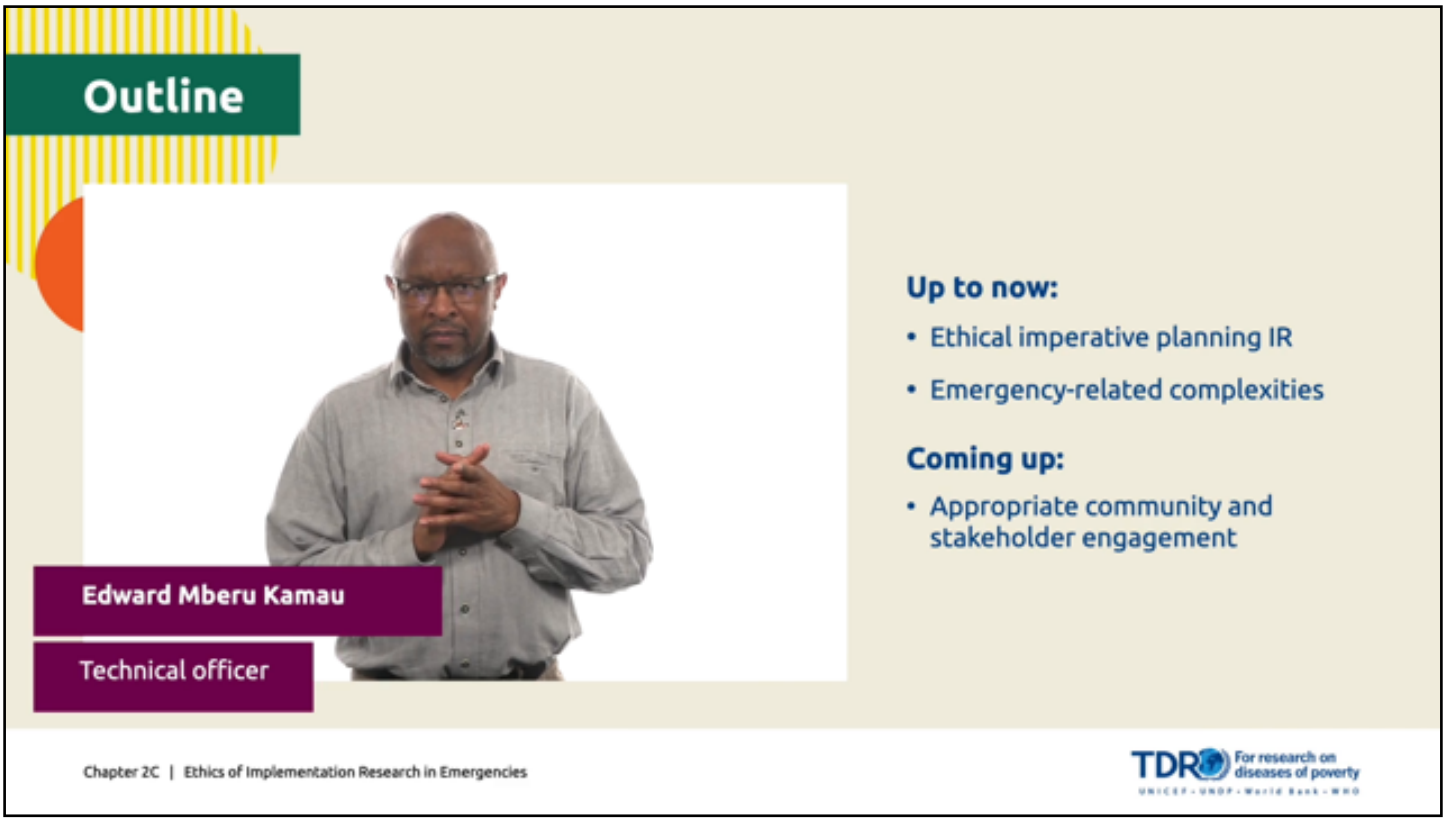


careful planning of implementation research and have considered the added

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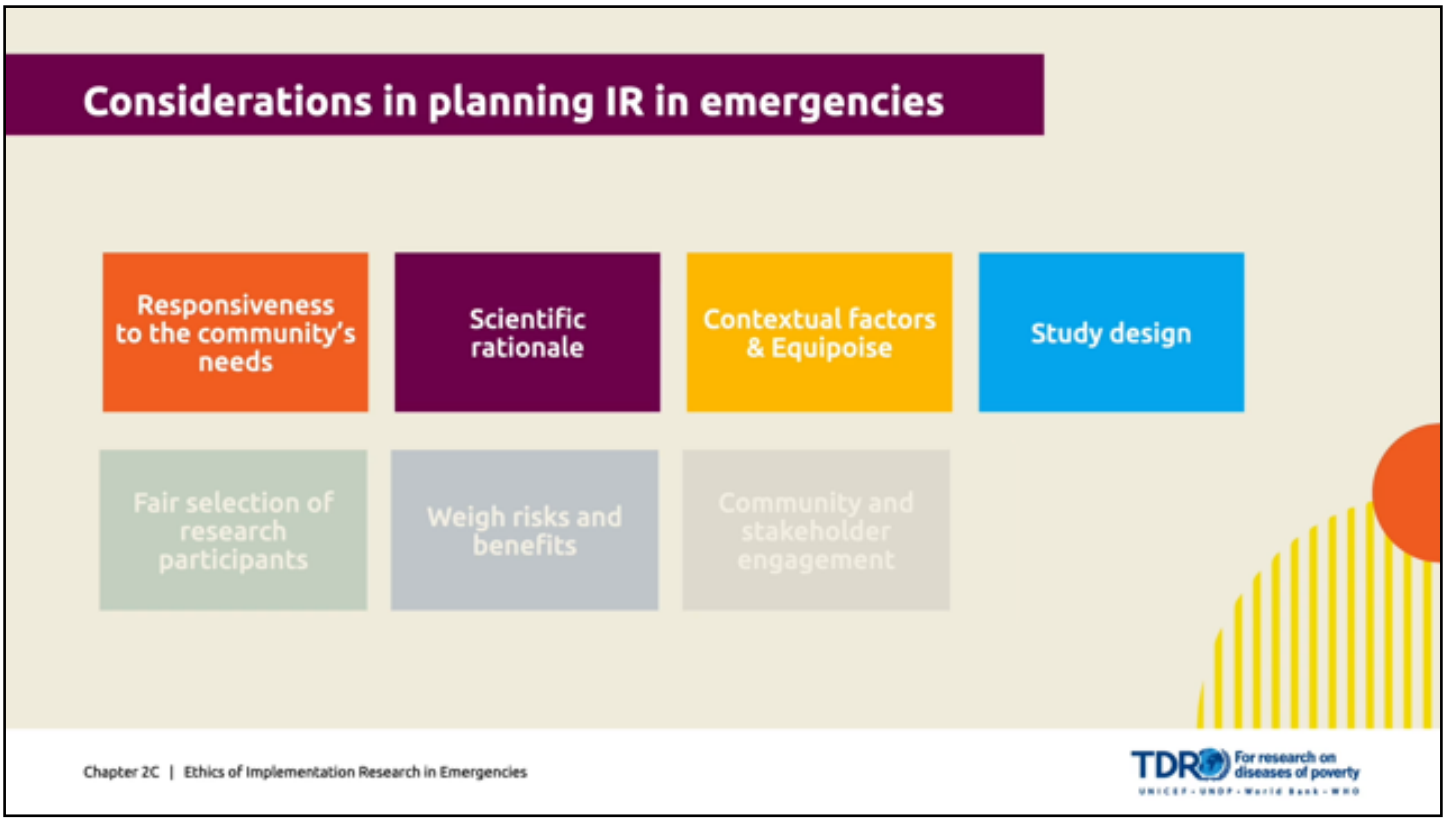


complexities imposed during emergencies, we will turn our attention to the ethical imperatives of ensuring appropriate community and stakeholder engagement to

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support optimal study planning. As we have reviewed in sections 2a and 2b, to support ethical conduct of implementation research in emergencies,

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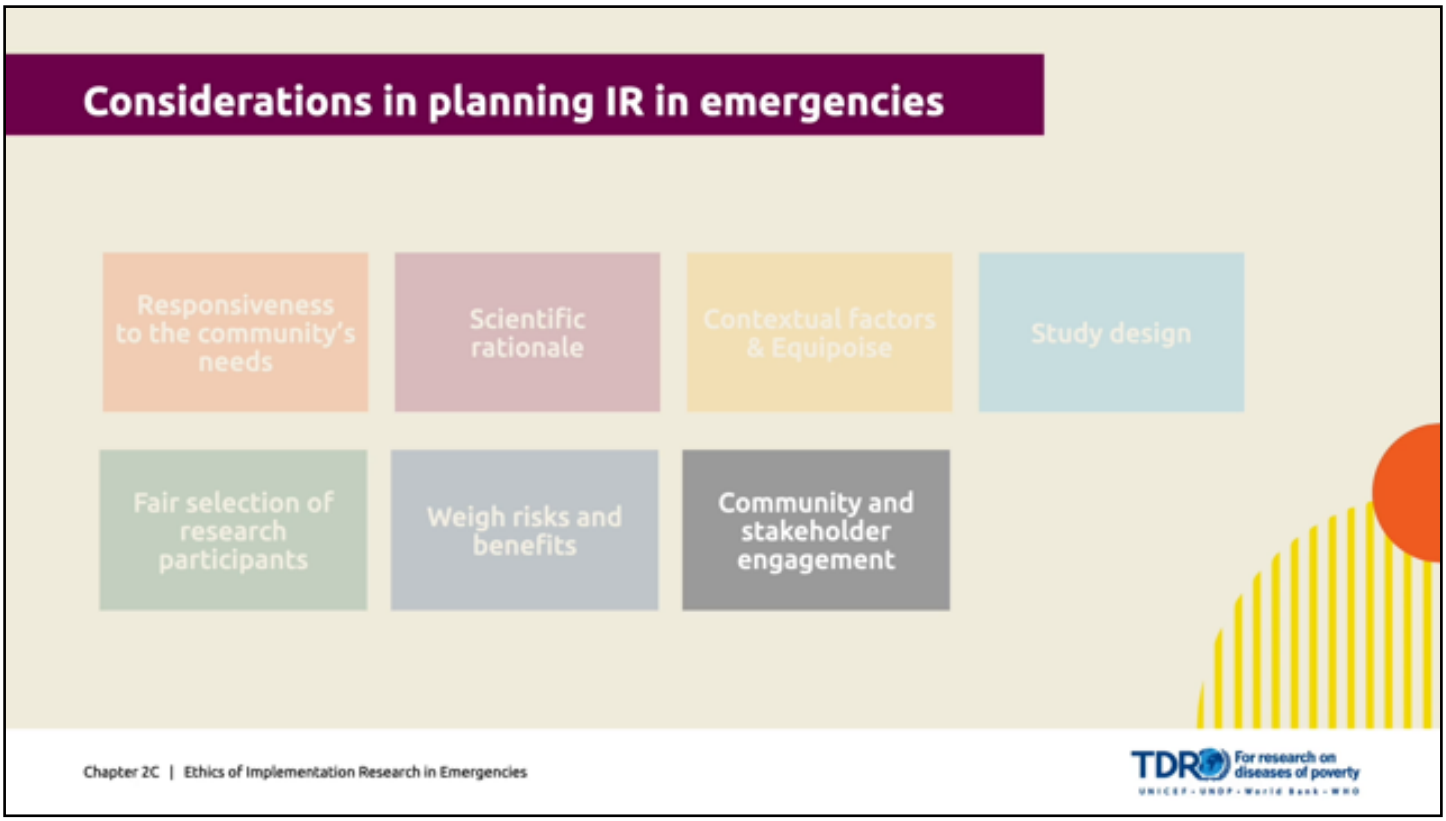


the research questions must be relevant for the community and the study must be scientifically sound. In addition, we discussed the importance of

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upholding the research ethic principles of justice – doing good and avoiding harm – which may be more complex to achieve in emergencies. Rapid understanding of the study context and stakeholder roles and perspectives

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1m 13s

Considerations in planning IR in emergencies



Chapter 2C | Ethics of Implementation Research in Emergencies

TDR For research on diseases of poverty
UNICEF · UNDP · World Bank · WHO

is a key foundation for meaningful implementation research. The required level of communication and trust between researchers and

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1m 36s

Considerations in planning IR in emergencies



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communities may be harder to achieve in an emergency, but

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1m 44s

Considerations in planning IR in emergencies



Chapter 2C | Ethics of Implementation Research in Emergencies

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implementation research cannot succeed without high quality

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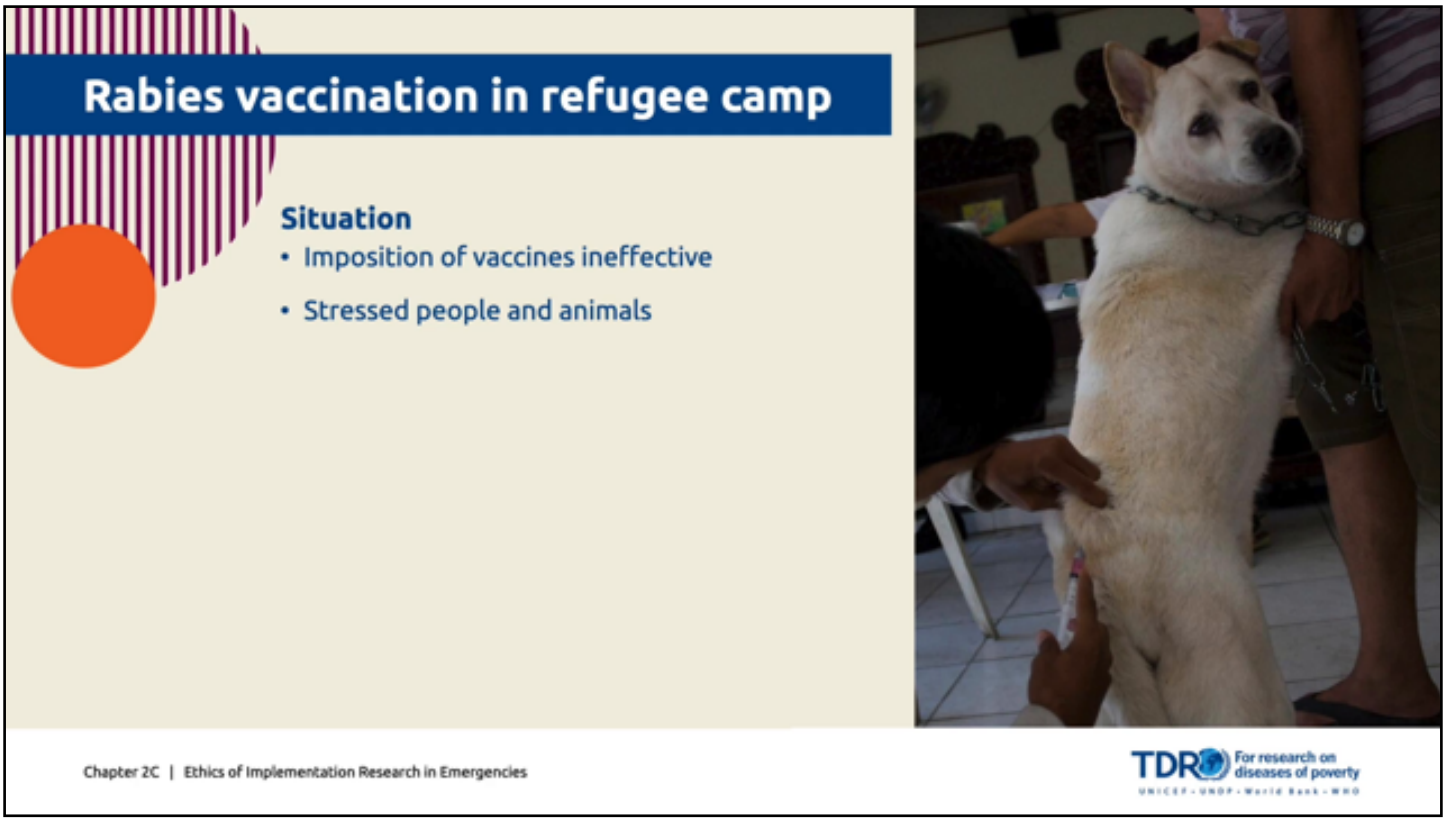


multi-stakeholder engagement. To understand the importance of community and stakeholder engagement, let us go back to the example of rabies vaccination for people

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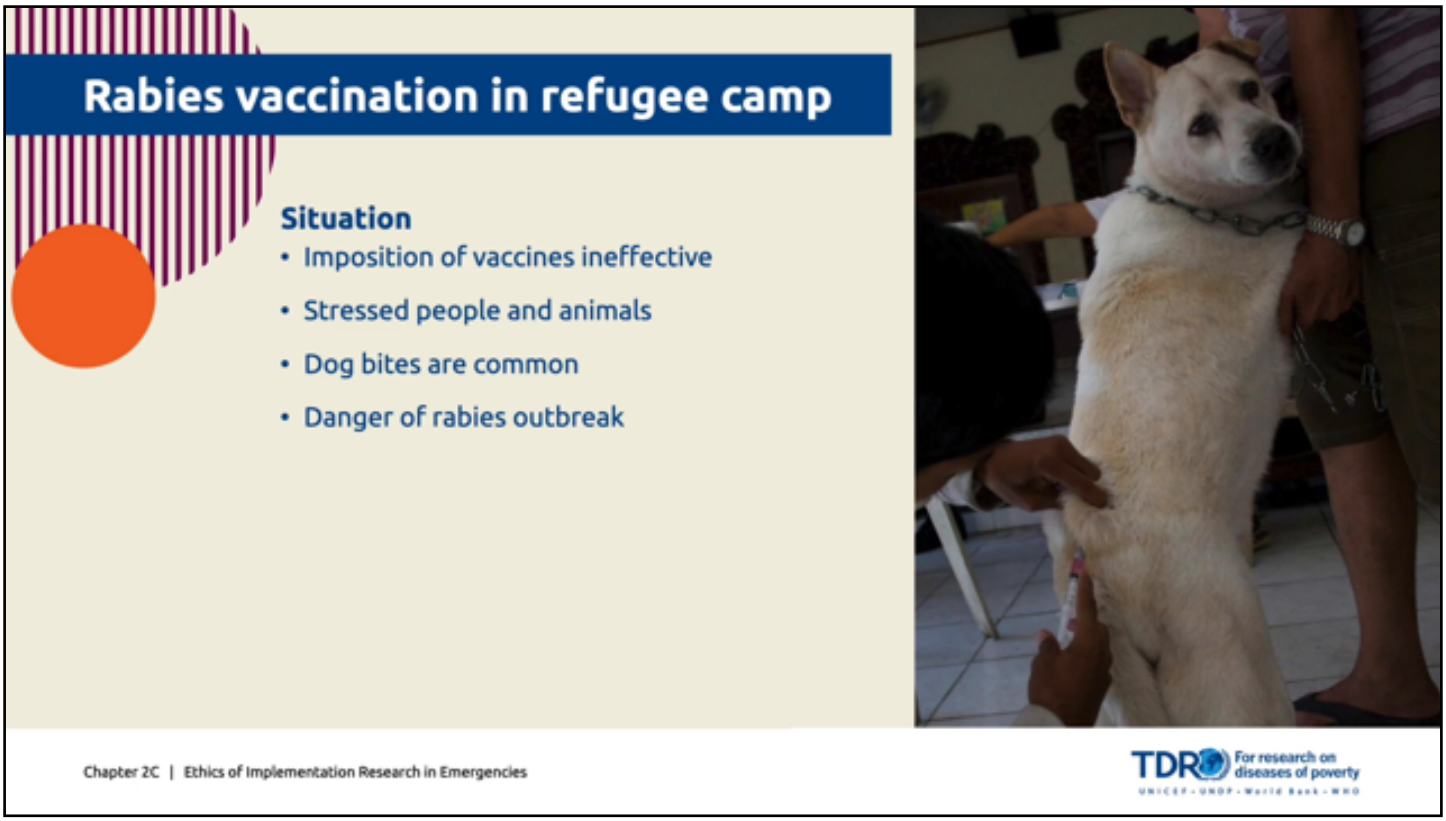


and dogs in a large refugee community in Uganda. The imposition of vaccinations from outside has not been effective. Even the

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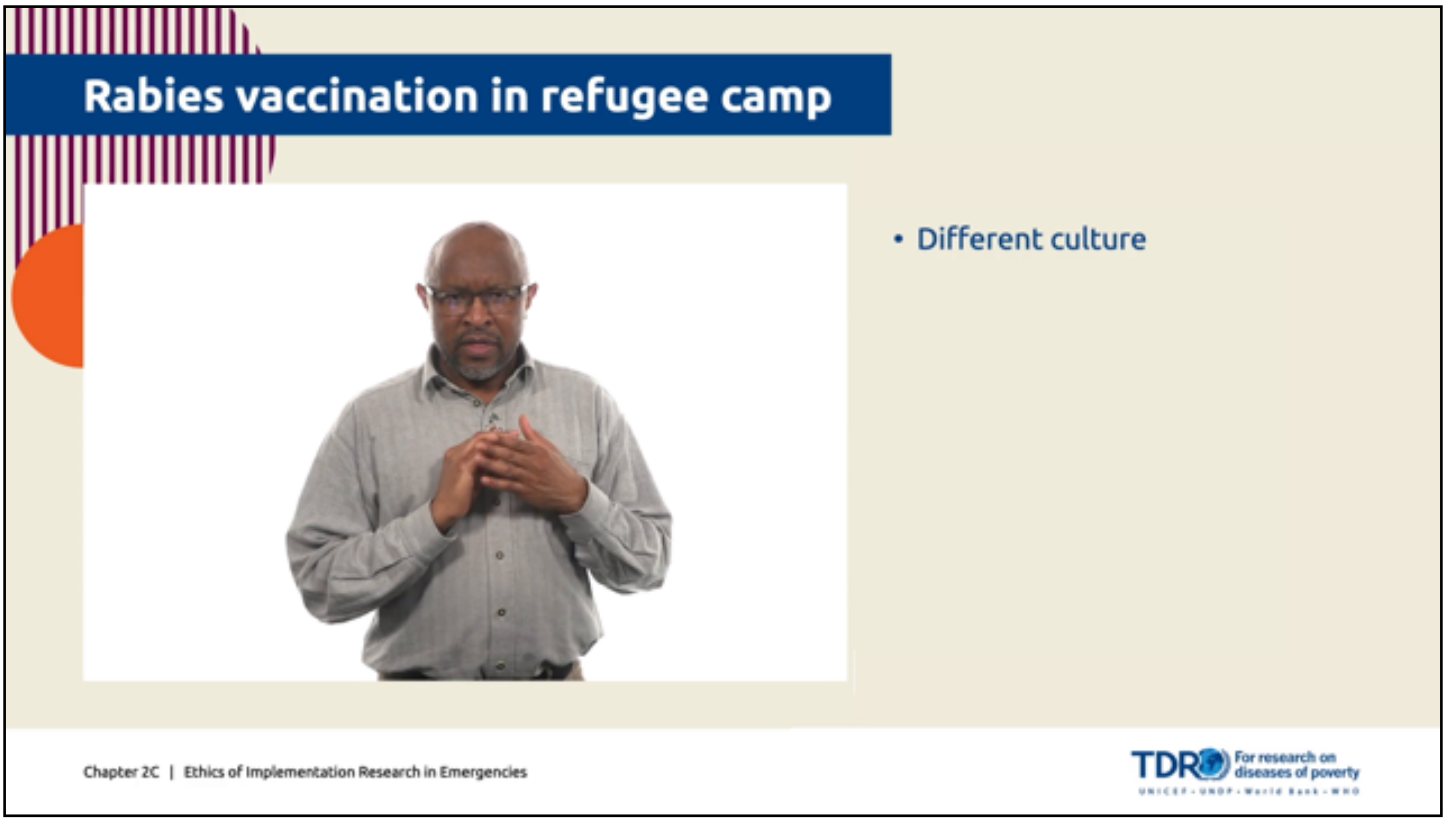


dogs seem more stressed in the chaos of the emergencies, and dog bites are common.

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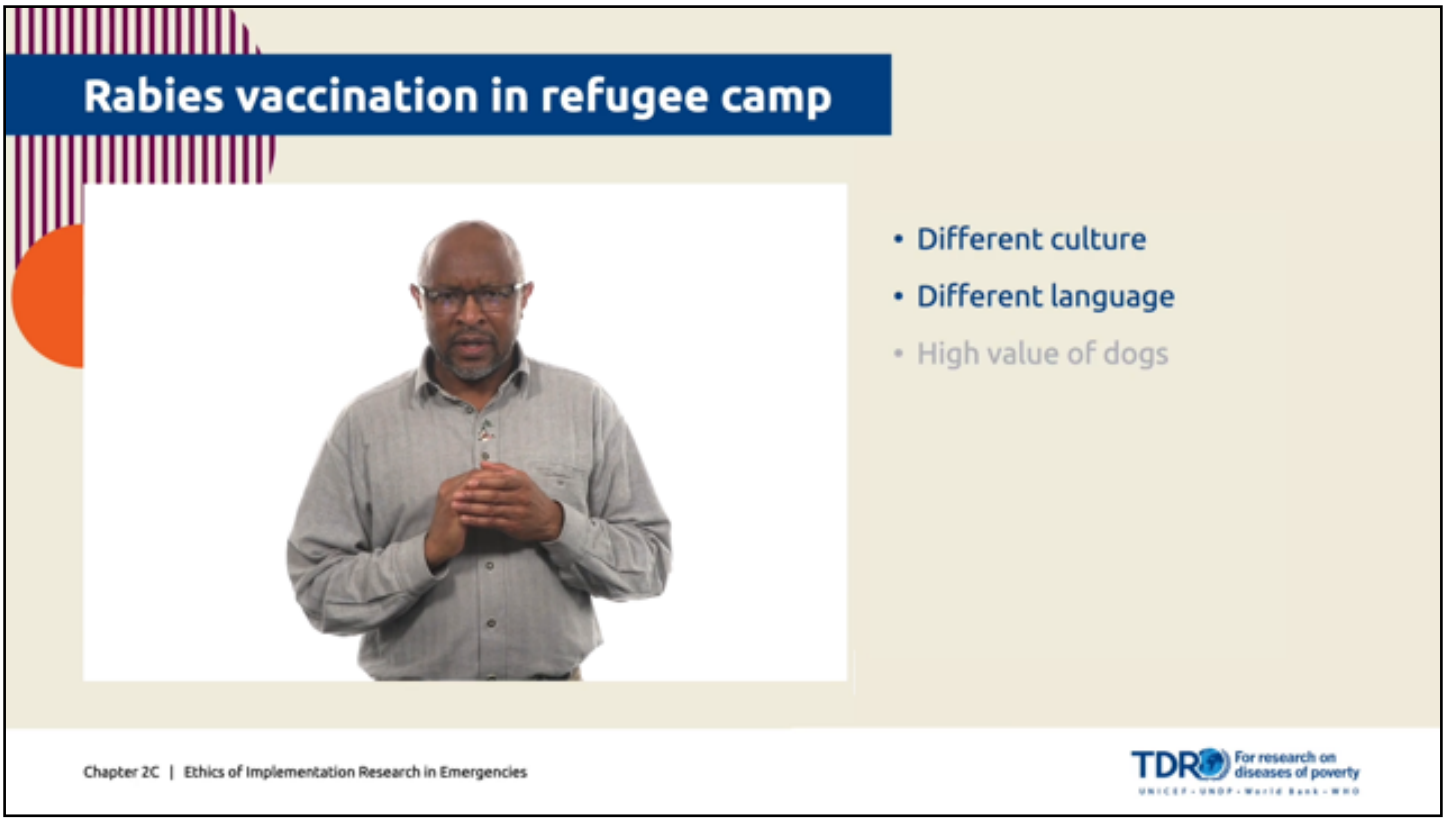


A rabies outbreak in the refugee camps would be extremely hard to contain. Implementation research is therefore urgently needed to understand the current barriers to

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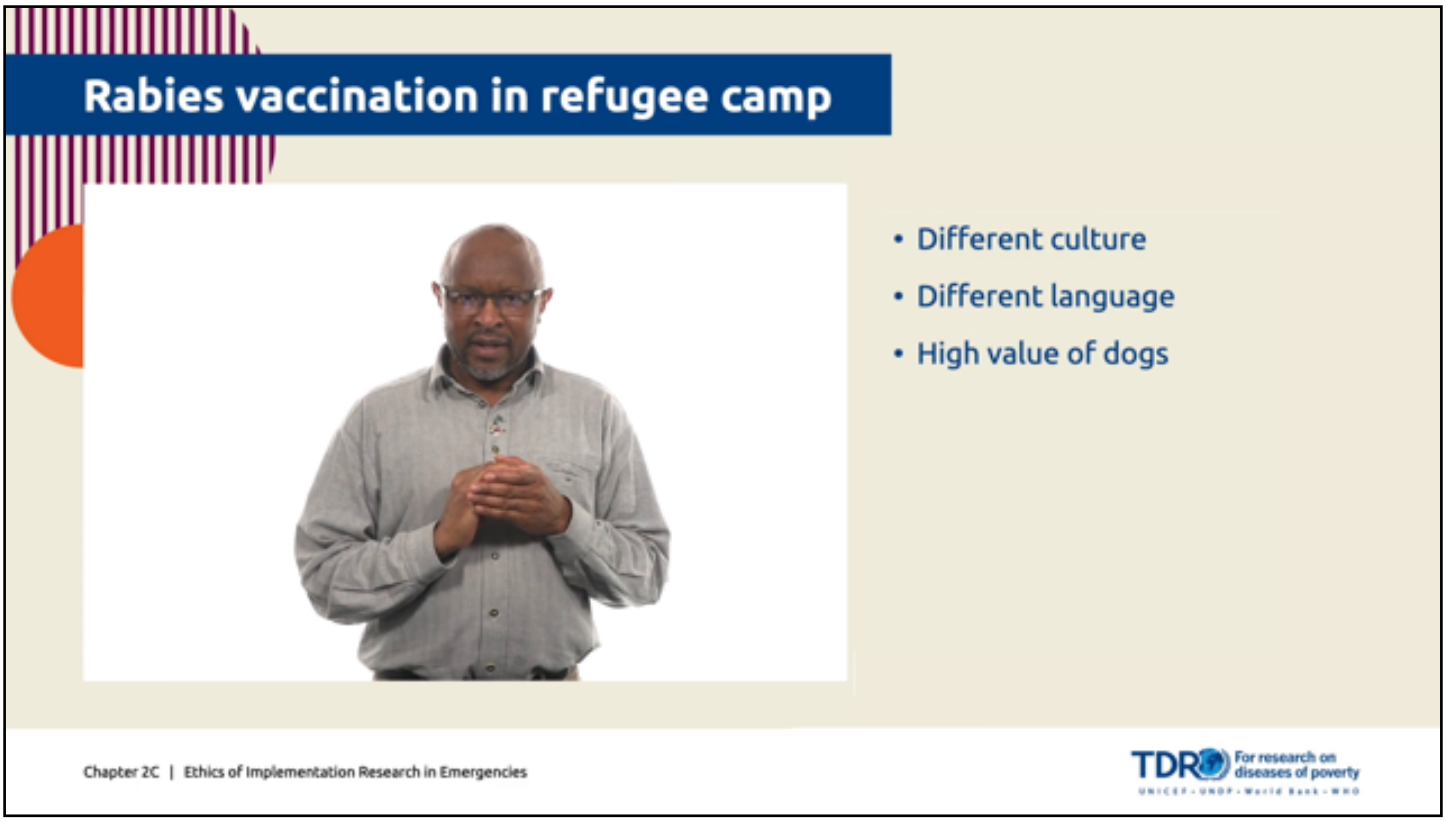


vaccination. The refugee community is from another culture and

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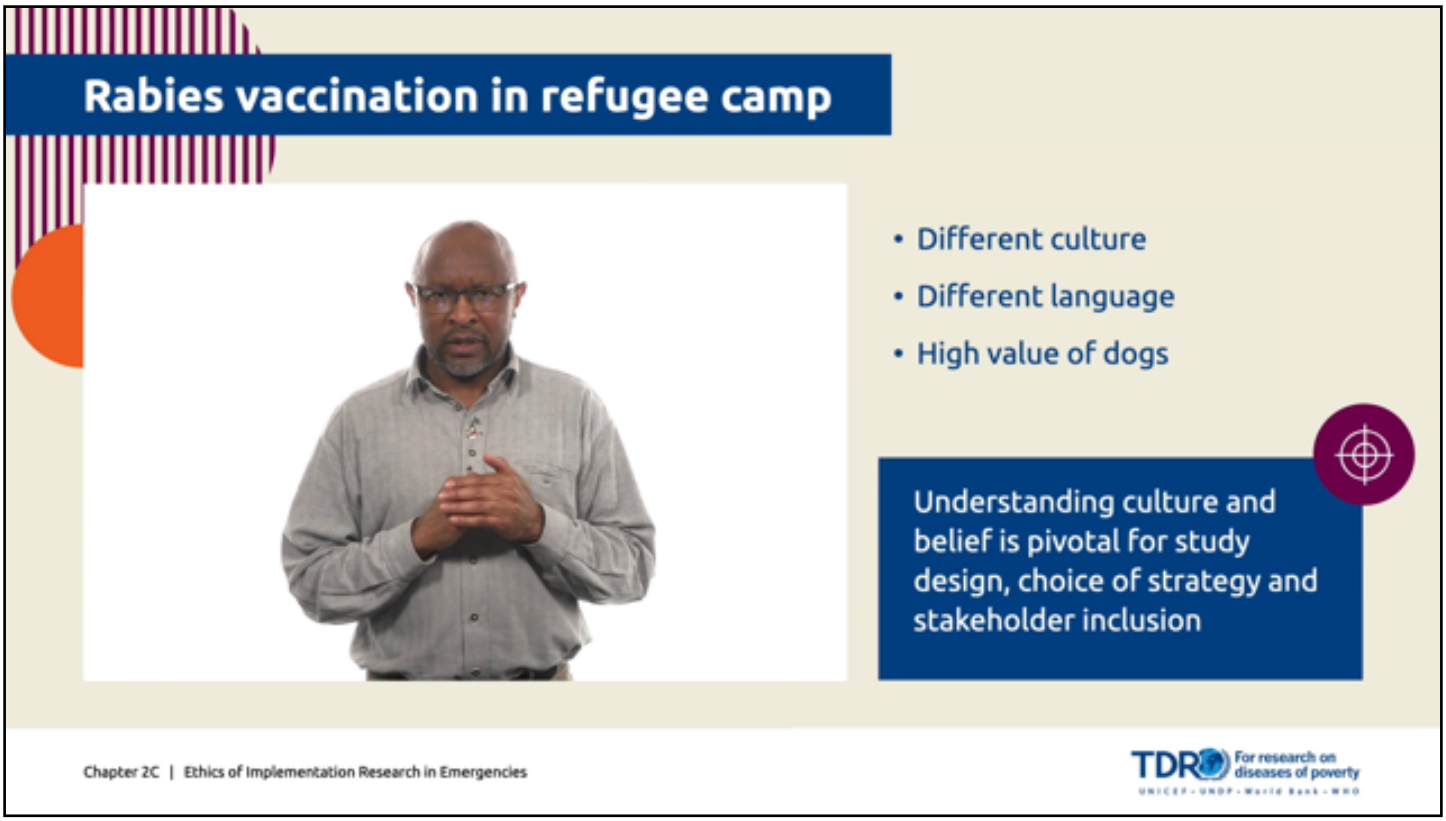


speaks a different language. They clearly value their dogs enough to have

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brought them with them as they fled. Effective and respectful communication is therefore needed to understand the community's beliefs, how best to design the implementation research studies, which strategies to consider and who to include

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3m 4s

Ethical imperatives for community and stakeholder engagement



King KF et al. Community engagement and the human infrastructure of global health research. *BMC Med Ethics 2014.* https://doi.org/10.1186/1472-6939-15-84
Lavery JV et al. Addressing ethical, social, and cultural issues in global health research. *PLoS Negl Trop Dis. 2013.* https://doi.org/10.1371/journal.pntd.0002227

as pivotal stakeholders. Thinking more about this example, one can recognise three key ethical imperatives in implementation research in emergencies which underlie the need for effective community and

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3m 24s

Ethical imperatives for community and stakeholder engagement



King KF et al. Community engagement and the human infrastructure of global health research. *BMC Med Ethics 2014.* https://doi.org/10.1186/1472-6939-15-84
Lavery JV et al. Addressing ethical, social, and cultural issues in global health research. *PLoS Negl Trop Dis. 2013.* https://doi.org/10.1371/journal.pntd.0002227

TDR For research on diseases of poverty

stakeholder engagement. The first imperative is building legitimacy for the implementation study. This requires that a project addresses a

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priority need of the community, of which there maybe many, and

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3m 58s



that the research process is acceptable to the community. The second imperative is to gain as true a picture as possible of all the

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4m 1s



contextual factors that may impact a study. Researchers must earn

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4m 18s



the respect and trust of the community and of all the stakeholders. Such respect is earned through transparent and clear communication and demonstration of accountability and trustworthiness on the part of the researchers.

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4m 27s

Ethical imperatives for community and stakeholder engagement



King KF et al. Community engagement and the human infrastructure of global health research. *BMC Med Ethics 2014.* https://doi.org/10.1186/1472-6939-15-84
Lavery JV et al. Addressing ethical, social, and cultural issues in global health research. *PLoS Negl Trop Dis. 2013.* https://doi.org/10.1371/journal.pntd.0002227

TDR For research on diseases of poverty

The third imperative, as we have discussed extensively in the prior chapter, is the necessity of identifying and managing the non-obvious risks and benefits. The risks, especially, may be greater in an emergency. To illustrate these points, let us think more about the rabies vaccination

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example. If, through appropriate engagement, the researchers are able to gain the trust of the refugee community, they may realise that the acceptability of vaccination for dogs and humans may be different, which may require separate approaches to improve uptake of both. On the other hand, the researchers may learn that the community is experiencing an outbreak of diarrheal diseases and is more focused on addressing safe

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5m 10s



food and water. In this case, research focused on increasing safe hygiene practices in the refugee camp may need to be prioritised

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and addressed before addressing the rabies question. If rabies is indeed a priority concern for the community, then engagement to identify potential benefits and harms will support transparency and accountability. For example, and a non-obvious benefit for the community may be a broadening of the trust in the health system and authorities. A non-obvious benefit for the vaccine manufacturers, the refrigerator sellers, or transportation companies may be profits generated by a large increase in demand for the vaccines. Non-obvious harm for individuals may result from stigmatisation of those who do or do not accept the vaccination, depending on whether the community remains resistant. A further unanticipated harm may include malnutrition if the community relies on eating meat from unvaccinated dogs as a choice of food. How likely these benefits and harms would be and how to manage them can only be determined through engagement with all the relevant stakeholders, which we will discuss in

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6m 8s



more details in a few slides later. As we can all clearly imagine or may have experienced ourselves, communities in

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7m 42s



emergencies may be more fearful and vulnerable, but may also probably have an entire set of new needs which need to be met urgently. To achieve the fundamental goal of building trust between the implementation research team and

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7m 56s



the community in an emergency, multiple ethical norms can guide this process. The most fundamental ethical norm upon

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summary

8m 13s



which all others rest is respect for persons. Researchers

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summary

8m 25s



must recognise the community's right to be involved in decisions that will affect them,

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8m 28s



especially in an emergency. Preexisting presumptions may no longer be relevant. Beneficence or doing good and avoiding harm must

notes

summary

8m 42s



be the primary goal. This requires that the community participates in

notes

summary

8m 54s



deciding what is good for them. As we have discussed in earlier chapters, being careful not to exploit or leave out vulnerable individuals or groups is a key component of justice in research. Communities themselves may be in a better position to determine fairness and representation of their own needs, especially in an emergency where fear and mistrust or

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9m 1s



even a level of despair may be prevalent. Researchers must be

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summary

9m 36s



clearly accountable to the community for their actions and decisions, which

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summary

9m 37s



requires transparent communication with clear and accurate disclosure of relevant information.

notes

summary

9m 49s



Solidarity with the community should be demonstrated through sharing responsibilities

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9m 55s



and acting to address the needs of those who are most vulnerable. This may be hard to achieve in an emergency if the researchers cannot be present on site, but can be developed through fostering strong local partnerships.

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10m 2s



Fundamental to the public justification of a study, especially when conducted in an emergency,

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10m 24s



is the imperative to ensure that any effective and acceptable

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10m 26s



intervention will be equitably and sustainably accessible

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to all those who need it after the study. Importantly also, implementation researchers must realise that circumstances on the ground in an emergency may change from day to day. Ongoing community and stakeholder engagement throughout the study is therefore crucial to ensure ethical research practice.

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10m 49s