Course material

Course:

Ethics in Emergencies

Video:

9b Data handling

Concepts (extracted from automatically generated subtitles):

Implementation research. Ethical obligation. Human samples. Planning stages of implementation research. Risks of breaches of privacy. External researchers. Ethical implications of such reuse. Research participants. Conduct of a study. Data. General chaos. Specific community of institution. Research findings. Indicator of uptake of an intervention. Emergencies.

to video sequence search
(within Ethics in Emergencies.)

to video



...

notes

summary

0m 0s



Data collected during implementation research in emergencies is precious. Researchers

notes

summary

0m 1s



have an ethical obligation to ensure that the data is handled and used correctly. Highly relevant when implementation research is conducted in emergency is the issue of

notes

summary

0m 13s



who owns the data. In the general chaos, external researchers and funders may consider that the data is theirs, as they can use it more

notes

summary

0m 25s



efficiently. As the data was generated in a specific community of institution, however, the

notes

summary

0m 37s



research participants should also have some ownership of the data and have a say in what can be done with it. Transparent community and stakeholder

notes

summary

0m 49s



engagement is required during the planning stages of implementation research to be conducted in an emergency to ensure that all involved are clearly informed

notes

summary

1m 1s



as to what data will be collected and how and by whom this will be used. Researchers are then ethically obligated to adhere to the

notes

summary

1m 13s



agreed strategies. The risks of breaches of privacy and confidentiality in emergencies are higher, as we have discussed. These risks may increase further if

notes

summary

1m 25s



data is to be shared after the study. Any plans for data sharing needs to be

notes

summary

1m 37s



done transparently and with the permission. The urgency of the need for data in an emergency cannot be used as an excuse to circumvent these norms.

notes

summary

1m 49s



Misinformation is rife during emergencies, and data getting into wrong hands may have critical consequences. If human samples are collected during implementation of

notes

summary

2m 1s



research, for example, if viral loads or drug levels may be used as an indicator of uptake of an intervention, researchers have the ethical obligation to store these safely.

notes

summary

2m 13s



Again, respecting privacy and confidentiality. As was observed during the Covid- 19 pandemic, the world becomes thirsty for data and samples in

notes

summary

2m 25s



emergencies. Therefore, there may be the temptation to reuse data or

notes

summary

2m 37s



samples to answer research questions for which they were not originally collected. Researchers must be aware of the ethical implications of such reuse and mere

notes

summary

2m 49s



existence of data or samples does not permit reuse without ethics oversight. Ethical standard for sample and data sharing cannot be lowered in emergencies.
Implementation

notes

summary

3m 1s



researchers therefore have the obligation to request renewed ethics approval to determine if

notes

summary

3m 13s



reuse is ethically acceptable. In an emergency, the requirement to reconsent individuals for reuse of samples or data may be logistically difficult, and may prelude

notes

summary

3m 25s



data or sample sharing if considered a risk to the participants. In summarising the ethical responsibilities for implementation research after the conduct of

notes

summary

3m 37s



a study in an emergency, it is helpful to remember that the goal of implementation research is to translate what we know into what and how we do. Crucial to bridging this

notes

summary

3m 49s



gap is knowledge communication. Implementation researchers have an ethical obligation to disseminate their research findings, and to ensure that these are used to scale up

notes

summary

4m 1s



effective and sustainable interventions, such that the communities that participated in the

notes

summary

4m 13s



research share in the benefits. Researchers cannot cut corners. Ongoing stewardship of the data and samples generated during implementation research

notes

summary

4m 25s



in an emergency is a key responsibility of implementation researchers. Privacy and confidentiality of research participants must be maintained, and any data or sample

notes

summary

4m 37s



sharing must be done safely and ethically. We have now come to the end of the chapters outlining the ethical issues relating to the planning, research and

notes

summary

4m 49s



post research phases of implementation research conducted in emergencies. To put all

notes

summary

5m 1s



we have learned into practice, in the next chapter, we will work through the ethics review of an implementation research study to be conducted in emergency so that you can put this into practice in your future work.

notes

summary

5m 13s