Course material

Course:

Ethics in Emergencies

Video:

8b Care of research team, privacy and confidentiality

Concepts (extracted from automatically generated subtitles):

Implementation research. Local research teams. Local researchers. Ethical obligation. Local areas. Such compromises. Further important ethical obligation. Ethical principles. Crowded spaces. Last section. Research teams. End of the chapter. Research process. Emergencies. Importance of these issues.

to video sequence search
(within Ethics in Emergencies.)

to video



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As we've mentioned already, in implementation research conducted in emergencies, the local

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research teams form the backbone of the team. In emergencies, where movement may be restricted or local areas may be inaccessible, these individuals may be putting themselves at risk. They may be

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being exposed to risks associated with the research while also being personally affected by the emergency. As such, there's an ethical obligation based on solidarity and fairness to

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protect the local researchers. Importantly, local researchers should be respected as equals within the research teams. Their insights may well be game changers, and they will be best positioned to

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understand how the emergency circumstances may impact the research process and the communities. It is likely, however, that these local researchers are being pulled in all directions, with many

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having clinical commitments, research commitments and family commitments. Clinicians, especially, may experience moral distress if they feel that resources are being directed away from clinical

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needs towards the research. This may all lead to burnout. Based on the principle

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of solidarity, implementation research must therefore be accountable for considering how best to support local research teams in emergencies and to implement strategies to mitigate burnout and moral distress. Hand in hand with acknowledging the pressures and supporting local

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researchers during implementation research conducted in emergencies is the fair and equitable acknowledgment of their contributions. Local researchers should be included at the

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decision making table and their input valued and taken into consideration. As conditions change fast during emergencies, it is likely that some compromises will need to be

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made along the way. It is important that the ethics of these compromises be carefully considered and that ethical principles are adhered to. Ultimately, deciding

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how to reach such compromises requires solidarity, respect, and transparency. This can be strongly supported by involvement of the local researchers and through the imperatives of

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community and stakeholder engagement. Similarly, when implementation research is conducted in emergencies, data or samples collected may be

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easily shared or taken out of the country without appropriate respect for local ownership and intellectual property. Such practices are not only wrong, but will also, over longer terms,

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erode trust. We're all aware of local authors from lower resource settings and junior researchers

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not being given appropriate recognition in publications. Based on fairness, respect and solidarity, this is not acceptable. The risk of these omissions may be higher in emergencies.

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A further important ethical obligation to consider in implementation research during emergencies is the fairness of allocation of research funding. As implementation research must

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address research questions that are relevant to the community on the ground, as a matter of justice, research agendas should not be driven by external funders. Local ethics review

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may serve to monitor local research priorities and alignment with funder agendas. Last but not least, a very strong obligation in implementation research conducted in emergencies

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is upholding the ethical principles of respect for privacy and confidentiality. We discussed the importance of these issues as they're related to informed consent and respect for participant

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autonomy. These issues do not end there, as interaction with research participants and data collection and storage are ongoing, privacy and confidentiality must be priorities throughout the

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research process. Given the chaos and haste that prevail in emergency, secure processes for ensuring the confidentiality of data collection and storage may be compromised. At

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the same time, the vulnerability of all the research participants is heightened and the risks of stigma and discrimination are higher. As we've discussed earlier, implementation

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researchers must consider how they will obtain and document informed consent, being mindful of the potential risks should any paperwork fall into the wrong hands. The consequences of breaches

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and confidentiality may be dire in emergencies. These may lead, for example, to revealing the

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location of persecuted groups or identifying potentially infectious individuals, among others. Similarly, if a study requires patients to be interviewed or to respond to surveys, privacy and

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confidentiality issues may differ if these are done in person, online or by telephone. In crowded spaces such as refugee camps or emergency rooms, for example, privacy will be very

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challenging to maintain. In emergencies, it's also more likely that data is stored on paper or on devices which may be lost, stolen or damaged, and this may compromise privacy and

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confidentiality as well as loss of data. High staff turnover during emergencies may also be a weak link in terms of data stewardship and maintaining privacy and confidentiality.

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Extra vigilance is therefore required to maximise privacy and confidentiality in emergencies.

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Researchers have an ethical obligation to install additional checks and balances to preempt dangerous breaches in emergencies. To briefly recap this last section, ongoing monitoring and

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evaluation are key for researchers in emergencies to keep their fingers on the pulse of the research, given the fluidity and instability of the research context. Implementation

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researchers must also realise that obligations to support local research teams may increase in emergencies, as they too may be affected personally as well as professionally.

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Emergencies increase the risks of breaches of privacy and confidentiality. Extra vigilance is required to mitigate these. We have now come to the end of the chapter on ethical issues that are

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relevant during the conduct of implementation research in emergencies. The ethical obligations of implementation researchers do not end with the end of data collection. In the next chapter, we will delve further into the ethical issues which apply to the post-research phase.

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