

Podcast script

Chapter 3.4: '*Ethics in research*' by Caroline Dubois, Katharine Wright and Michael Parker

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Asta: Hello. Today I'm joined by Caroline Dubois, Assistant Project Director at GX Foundation, Hong Kong and Adjunct Tutor at The Chinese University of Hong Kong. Caroline is one of the authors of the Ethics in research chapter in the WHO Guidance on Research Methods for Health Emergency and Disaster Risk Management.

Asta: Hi Caroline, thanks for joining me.

Caroline: Hi, it's nice to be here.

Asta: This chapter is about the importance of ethics in research and ethical considerations for research in emergency and disaster contexts. Could you start by telling us the role and relevance of ethics in research?

Caroline: Ethics. Research and ethics is about collecting good data to generate high-quality evidence that can impact people's wellbeing and lives. Ethics also encourages transparency; it reinforces a balanced partnership between stakeholders and mitigates against harmful results. But ethics goes beyond just a process of obtaining ethical approval from a committee; it actually needs to be considered throughout the entire process from design, implementation, publication, through to information sharing. So, this is particularly important in health EDRM research which is being done under emergency contexts, maybe under a time pressure or geographical or cultural barriers.

Asta: The standard or normative guidance for research ethics is long-established and already includes these elements, so could you elaborate in what ways are the standard guidance limited in the context of health emergencies and disasters?

Caroline: Right, so emergency settings create really unique challenges in logistics, security, resources, time, and has a lot of competing priorities that mean standard procedures designed to run in controlled settings are not flexible to adapt to these uncertainties. However, pressure is not an excuse for bypassing ethical values and researchers and communities still have to be protected. So ethical requirements in health EDRM should be adapted, adaptable and flexible whilst ensuring ethical integrity, under such complex circumstances.

Asta: To hear research standards aren't lowered for complex circumstances is great to hear. In one of the examples you mentioned is the West African Ebola outbreak. So the rising fatality pushed the global community to use unregistered interventions and a WHO review panel concluded that it was ethical to offer experimental interventions during crisis.

Caroline: Exactly, so researchers have to consider the broader benefit than a piece of research would have for overall societal good. In this case, the researchers were comparing the public health need and the risk of using experimental interventions in a situation where no other intervention was available. These exceptions come with requirements so researchers in the situation have to share data rapidly and transparently. Interim data about the interventions had to be promising in terms of their efficacy and safety and of course, the fact that the drugs for the vaccine were unregistered had to be made really clear to the participants.

Asta: So, what you are saying is the researchers have to balance the risk and needs of the community as well as having an obligation to consider and weigh out the value, feasibility and value of the work?

Caroline: Exactly. A value is about considering the added benefit to human wellbeing. This can include the value of prioritising one piece of research over another. Feasibility is about the timing and purpose of the research beyond just the desire to collect data. And validity is about the reliability and usability of the findings.

Asta: Those are a lot of factors to consider and they're all closely linked with research participants' selection, particularly in emergency settings. Marginalised populations are at risk of being excluded due to demographics and accessibility barriers. How does this jeopardise the validity of research results?

Caroline: Exclusion creates a risk for knowledge gap, so often times of disaster create geographical barriers. Also, there are many complexities around reaching people who have recently suffered trauma. Failure to include these groups, however, means failure to understand the impact of the emergency that has been felt across an entire population. So, this would jeopardise the validity and even the value of the research.

Asta: So, when including these marginalised groups in research, especially following traumatic events, it is important to protect their interests, particularly if the research can be intrusive or focuses on or highlights their vulnerability. Where are the ethical considerations that researchers should follow in order to protect these communities?

Caroline: Increased vulnerability is almost inherent to emergency research. Participants would have just been through an extremely difficult event; researchers then have to be vigilant about potentially misunderstanding or potentially exploiting the community. So, a breach of trust can harm the participants and the community as well and it can compromise the research and potential outcomes. Because of this, privacy and confidentiality have to be respected because the community should not be exposed to further harm or stigmatisation as a result of the research that you are doing.

Asta: But how can trust and confidentiality be kept?

Caroline: This can be done in several ways, such as giving the option to withdraw from research, being explicit about the way the research is being used, protecting the data particularly identifiable data and making sure that you have informed consent. So, it's really important to remember that these communities are actual research collaborators and not just a source of data.

Asta: But going back to informed consent, how is this important in research?

Caroline: Informed consent is where research participants are given all of the information that they need to clearly understand the process, objectives and the risks of the research so that they are able to decide if they want to participate without coercion. Research can be really intrusive and to mitigate against discomfort or harm to the participants, researchers have to relate all necessary information in a transparent way.

Asta: But how do you adapt informed consent in the context of health EDRM research?

Caroline: Getting informed consent in a health EDRM context can be practically challenging, where someone's desire to survive or their desire to receive care, or even the perception of receiving

favours can trump someone's perception of risk and harm. Research managers have to put safeguards in place to ensure that populations are not being exploited.

Asta: So, to engage communities in the population can be a strong factor in ensuring ethical integrity and building trust between participants and researchers? What are some ways researchers can effectively engage communities?

Caroline: Researchers should aim to build reciprocal and collaborative relationships that are based on trust and transparency. So, make sure you build community engagement into your research that will allow you to understand local experiences and practices which will, in turn, allow you to attain impactful results. You also have to understand any gaps in health needs, access to care, gaps in infrastructure and other areas of need. One way to do this is to engage with a select group of representatives from the community who offer advice throughout the planning and implementation processes.

Asta: When collecting sound data, what can other stakeholders like managers and funders do to uphold ethical integrity?

Caroline: Managers and decision-makers, including research funders have a responsibility to steer research to where the need is. Managers are accountable for the safety and wellbeing of the research team, for example, and this will include providing them with the appropriate training in how to manage ethical issues on the ground. Funders, on the other hand, they have oversight on the projects. They can make sure there is no duplicative research on the same community that can lead to research fatigue on the participants. National governments can play a role in pushing out data from research and they can ensure that these results turn into very impactful policy that will be able to mitigate against future risks.

Asta: And regarding research governance, what is the role of the research ethics committees?

Caroline: Ethics committees uphold institutional and international standards for ethics to protect against the risk resulting from research. So, these committees have responsibility for being timely and flexible in the context of emergencies. Currently there's no real consensus about what this adaptability looks like; this is definitely an area where further work is needed.

Asta: And that's understandable as each emergency and disaster have their own unique set of challenges but before we finish, what do you think are the important findings or remarks that came out of this chapter?

Caroline: I think that ultimately successful outcomes in research which positively impact health and wellbeing rely on ethical practices to ensure validity, accountability and sustainability throughout the whole process. So, mutual respect and experience sharing between researcher and community is really important because this builds ownership and capacity in the community that will allow them to mitigate against future risks.

Asta: Thank you very much for sharing your insights in ethics in research. It's been a pleasure talking to you.

Caroline: Thank you.