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The intricate ethics of participatory research: negotiating partnership, power and boundaries

Participatory research is becoming increasingly popular. This entails people with direct experience of, or interest in, the topic of study playing a role in all or some of the research design and process. This presentation will discuss some of the ethical challenges arising in research that entails academics or professional practitioners working together with users of health and social care services and/or members of community-based groups. It may be tempting to assume that potential ethical challenges (e.g. avoiding exploitation, ensuring mutual respect, agreeing ownership of intellectual property) can be anticipated, mitigated in advance and checked off by Research Ethics Committees or Institutional Review Boards. However, this rarely reflects the messy reality of what happens in practice.

This presentation outlines some of the day-to-day and unexpected ethical challenges negotiated by people from different backgrounds working together as co-researchers. It draws on 28 case examples from around the world, collected for a forthcoming book on ethics in participatory research. Many are accounts of 'small' issues occurring during the research process, often not reported in publications, for example: should a community researcher in Southern Africa adapt research questions to avoid hurting people she knows?; how should a Dutch academic respond to a community based co-researcher's request to correct her written language?; where are the boundaries between 'friend' and 'co-researcher' for a UK PhD student?; should a Canadian researcher also function as a therapist during a research project? These questions are not easily answered by Research Ethics Committees, or through consulting ethical codes. The responses rely on careful reflection and deliberation between parties involved, based on particular circumstances and relationships. This requires a situated, relationship-based approach to ethics, drawing on an ethics of care, virtue ethics and the practice of 'ethics work', details of which will be outlined in this presentation.