

## **“Trust me I’m a researcher”: perspectives of researchers, research participants and research ethics committees**

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The human research ethics terrain can be fraught with challenges, particularly on the part of researchers. In most research settings, there are now well developed governance structures, codes of practice and policies that work to ensure the ethical conduct of human research. But how does this work in practice? I will present findings from two qualitative research projects that are part of a program of research on human research ethics in Australia. The first project examined how health researchers and human research ethics committee members understood and addressed ethical issues in research practice. This was based on 34 Australian ethics committee members and 54 health researchers. Although all participants agreed that the primary role of the ethics committee was to protect participants, there was disagreement regarding the additional roles undertaken by committees. Of particular concern were the perceptions from some ethics committee members and researchers that ethics committees were working to protect the institutions’ interests, as well as being overprotective toward research participants. Researchers believed that the process of ethics review was beneficial to them, allowing them to clarify their research, and offering a sense of protection when actually undertaking research. However, despite the considerable time devoted to ethics review, ethics committees and research guidelines were not seen as valuable resources for researchers undertaking research in the field. The findings pointed to poor relations and mistrust between ethics committees and researchers.

The role of trust in research was the focus of the second project. This project examined how trust is established and fulfilled by researchers; it investigated how participants decide to be involved in research, and the role that trust plays in this decision and subsequent research participation. Qualitative individual interviews with 19 researchers and 36 research participants involved in sensitive projects were undertaken; the majority of the projects were health-related. We also purposely included Australian Indigenous research projects because of the history of mistrust of research in these communities. In non-Indigenous research, research participants assumed trust, based primarily on institutional trust. This revalidates the importance of research ethics review and other institutional governance practices. However, for researchers, trust was much more explicit and comprised a complex set of ideas and practices. In contrast, in Indigenous research, the ways that trust was understood and managed was more closely aligned between researchers and participants. Because of the history of mistrust in Indigenous communities, breach of trust is more acute, with serious implications.

These findings provide important empirical evidence of the perspectives and experiences of three key stakeholders in the human research enterprise: researchers, research participants and ethics committee members. Based on this we can better understand current practices as well as point to ways of addressing ongoing challenges in the ethical conduct of research.