

Ethical Implications of Community-Based Participatory Research: Researcher Experiences

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Introduction

- Internationally there is an increasing focus in health policy on community participation (Kenny et al, 2013). Community-Based Participatory Research (CBPR) is considered an equitable, empowering partnership approach to researching vulnerable communities however greater attention must be given to ethical considerations (Minkler, 2008).
- □ CBPR was developed from Lewin's 1940s utilitarian mode to problem solving and the emancipatory style of Freire in the 1970s . From the 1960s the use of CBPR grew exponentially, addressing the challenges of supporting a fairer society (Minkler & Wallerstein 2008).
- ☐ La Trobe University is using CBPR to address health and wellbeing with three rural communities in Australia (Fig.1).



Fig. 1 La Trobe University – CBPR in 3 rural communities in Victoria, Aust.

Across the three communities team members were experiencing ethical challenges, which then prompted this study. The work of Banks et al. (2013) and Minkler (2004) provided a useful basis for our team to consider the issue of ethics in CBPR.



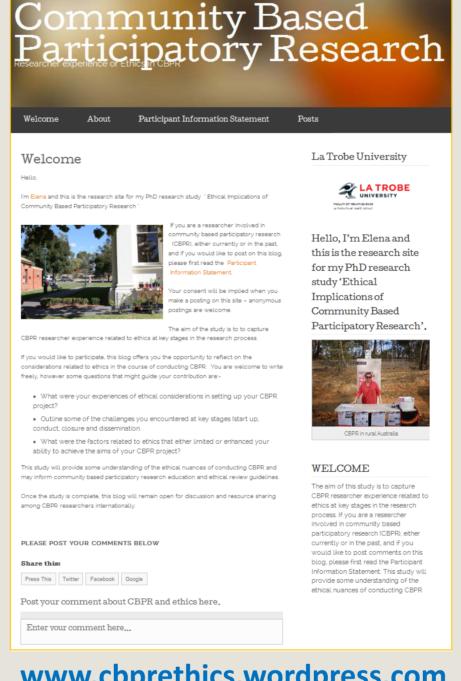
- ☐ Literature is mainly context or project specific rather than drawing from a broad selection of studies. There is only very little empirical work involving researchers.
- ☐ To address this gap in knowledge it was vital that first-hand accounts from CBPR researchers be gathered internationally.

Methods

- ☐ We designed an empirical study based on qualitative descriptive method (Sandelowski, 2000).
- ☐ In order to recruit across an international cohort of researchers, we chose to utilise a Web 2.0 platform for both participant recruitment and data collection (Snee, 2008).
- ☐ Participants are recruited using Twitter, ResearchGate and Facebook.
- ☐ A Wordpress.com blog was developed with dedicated use as the data collection site, in accordance with ethics approval. A participant information statement is included on the blog explaining that contribution to the blog implies consent. Blog settings were adjusted to enable anonymous participation.
- ☐ Participants have been writing on the blog about the ethical issues they have experienced at key stages of their CBPR process.



Twitter, Facebook and ResearchGate are used to recruit participants internationally.



www.cbprethics.wordpress.com
BLOG: Participants write directly on the blog
and can read other respondents' comments.









Blog currently open for researcher participation

Preliminary Findings

Ethical challenges discussed on the research blog:-

Informed Consent process

- Barrier to engagement
- Community intimidated by and wary of paperwork
- How to best provide a consent process that is meaningful for communities.

Compromised research rigour

- Negotiation of community cultural expectations with ethics approved processes.
- Negotiation of conflicting interests between research partners and individuals in the community.
- Other challenges discussed, related to professional boundaries and researcher identity, community disruption for advancement of a research agenda, researcher perceptions of marginalised populations, participant exclusion, and community capacity or willingness to accept power re-distribution responsibilities of CBPR.

Read about these at www.cbprethics.wordpress.com

Discussion

- ☐ Preliminary findings highlight recurring themes and challenges within even a small number of responses.
- ☐ The ethical challenges discussed on the blog are similar to those identified in our scoping review literature, suggesting some consistency in the types of issues encountered.
- Our findings will have implications for research training and best practice considerations for CBPR researchers in the future and inform recommendations to health policy on community participation to place it within an ethically sound framework.

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