

Centre for Human Bioethics

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Exploring the gap in healthcare for injured and uninsured research participants in the United States

Katrina A. Bramstedt

Unintended consequences of human research ethics committees: A re-voir workplace studies?

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No need to go! Workplace studies and the resources of the revised National Statement

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Beyond the IRB: Examining common but rarely explored ethical issues in psychosocial research

Robin K Matsuyama, Laurie J Lyckholm, M. Elizabeth Lowe and Michael B Edmond

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Exploring the gap in healthcare for injured and uninsured research participants in the United States

Katrina A. Bramstedt 11

ABSTRACT

In the United States 46 million people are uninsured and it is from within this population that many 'normal, healthy' research participants are selected. Research institutions and sponsors are not required to compensate or provide free treatment to participants when they incur research-related harm, and most studies do not stipulate the provision of free medical care to treat research-related adverse events. The consequence for uninsured participants is that they must assume these medical costs unless they successfully sue the study sponsor or research institution. This article discusses the matter of healthy volunteers becoming 'the sick' as a result of research participation, and proposes guidance for the informed consent process in order to optimize awareness about injury potential and injury compensation. Guidance regarding health screening for these volunteers is also presented.

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ARTICLES

Unintended consequences of human research ethics committees: Au revoir workplace studies?

Greg J Bamber and Jennifer Sappey 26

ABSTRACT

To protect the welfare and rights of participants in research and to facilitate research that will be of benefit, as well as protect them against litigation, universities and research-funding agencies in Australia adopted the National Statement on Ethical Conduct in Research Involving Humans (NHMRC 1999).¹ In many other countries there are similar statements. However, the ways in which such statements are often implemented by Human Research Ethics Committees (HRECs)² are in conflict with an important stream of industrial sociological research. This stream seeks to deconstruct workplaces and de-layer management rhetoric to understand the realities and complexities of the social relations of production. There is a pluralist basis for much industrial sociology that challenges the unitarist view of the workplace as essentially harmonious. While views of workplaces as being conflictual and exploitative have to be tempered with an understanding of the accommodative and co-operative nature of workplace relations, there is nevertheless a general recognition of acts of resistance, as well as those of co-operation. The way in which the National Statement is typically implemented in Australia means that many HRECs require written, informed consent, which in the first instance will usually be that of management. An unintended consequence is a research focus on consensus, which is at best one-sided and at worst seriously misleading. It is unlikely that managerial consent will be granted unless there is a 'good news story' guaranteed. This article explores the ways in which HRECs may influence workplace research. The publication of the revised National Statement provides a valuable opportunity not to be missed by HRECs to implement more effective and efficient practices which would not have the unintended consequences of the earlier version. This would deserve the support of researchers in industrial sociology and other branches of the social sciences.

No need to go! Workplace studies and the resources of the revised National Statement

Christopher Cordner and Colin Thomson

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ABSTRACT

In their article 'Unintended consequences of human research ethics committees: au revoir workplace studies?', Greg Bamber and Jennifer Sappey set out some real obstacles in the practices and attitudes of some Human Research Ethics Committees (HRECs), to research in the social sciences and particularly in industrial sociology. They sheet home these attitudes and practices to the way in which various statements in the NHMRC's National Statement [1999] are implemented, which they say is often 'in conflict with an important stream of industrial sociological research' in Australia. They do not discuss the recently completed revision of the NS. We undertake to show that the revised National Statement meets their concerns about research in industrial sociology, and to draw attention to the resources of the revised National Statement that engage with those concerns. A more general aim is to display the greater scope, in the revised National Statement, for researchers to show to HRECs that their research is justified by virtue of its reflecting the established methodology and traditions of their discipline. The revised National Statement, we suggest, provides for a more flexible and responsive approach than its predecessor to the ethical review of many areas of research.

Beyond the IRB: Examining common but rarely explored ethical issues in psychosocial research

Robin K Matsuyama, Laurie J Lyckholm, M. Elizabeth Lowe and Michael B Edmond

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ABSTRACT

This article discusses common ethical and practical considerations in psychosocial and behavioral research in healthcare. Issues such as appropriate objectives and intent, risk-benefit ratios, research design, and human subject protection are explored. The burden of ethical research design and implementation is placed on the investigator, rather than relying solely on institutional review boards to judge individual projects. The benefit of acquisition of knowledge must be balanced against the burdens of the research on society in general and human subjects specifically. Scientific replication of research is encouraged, unnecessary duplication defined and discouraged, and benefits of true collaboration outlined. Investigators are advised to consider the context, intent, purpose, implementation, and use of information when developing research. The concept of "researcher myopia" is defined as a common stumbling block. It is suggested that academic researchers also look to other disciplines, such as industry, for examples of research that is concise, cost-effective, and reliable.

BOOK REVIEW: Michael J Sandel, *The Case against Perfection: Ethics in the Age of Genetic Engineering*, Belknap Press, 2007.

Russell Blackford

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