

## Book reviews

**Faulkner, A.** 2004. *The ethics of survivor research. Guidelines for the ethical conduct of research carried out by mental health service users and survivors.* Bristol: Policy Press. 56 pp. £9.95 paper. ISBN 1-86134-641-7.

In the words of the author,

these guidelines aim to assist researchers, trainers in research skills and interviewers working from the perspective of mental health service users and survivors. They are intended as helpful guidance on ethical issues to be considered prior to the design and conduct of any survivor research project or research training programme.

The guidelines are based on consultation with fifty service users and survivor researchers through the use of questionnaires, interviews and focus groups.

It could be argued that the majority of issues covered have been previously debated within the literature on feminist, emancipatory and ‘user-led’ research method(ologies). Nevertheless, these guidelines make a timely contribution, bringing together fundamental ethical considerations in a concise and accessible format. It is essential that ongoing consideration of related ethical issues are continued to safeguard all those involved, particularly as the momentum of survivor-led research accelerates. However, regardless of the philosophical underpinnings of survivor research, it can be argued that these guidelines are relevant to anyone aspiring to meaningful service-user involvement. This may be throughout the research process, as is increasingly required by funding bodies and encouraged in the Research Governance Framework (2001), or in Public and Patient Involvement activities in accordance with Clinical Governance.

The guidelines are unpretentious and practical. They emphasize issues commonly referred to in health research, which in reality are often given insufficient consideration, such as transparency, training and commitment to change. They provide an ethical perspective on some issues more commonly

posited as ‘practicalities’ of survivor research. The need, for example, for flexible working arrangements and to plan a ‘realistic’ rather than ‘optimistic’ timescale for the research. Attention is drawn to the factors which need to be considered to ensure adequate and appropriate training be provided for survivor researchers. These include the context of the research, support mechanisms and debriefing for researchers. Further to this, the need for support and supervision of researchers is addressed in detail.

The necessity to provide specific emotional, practical and research-related support, that collectively amount to a comprehensive framework to ensure that the researcher is protected, is explored. It is suggested that emotional support is important since this type of work may be distressing and touch on personal experience, particularly in survivor research. Whilst the text recognizes the potential implications of lack of support to the individual researcher, it falls short of recognizing the implications on the resultant quality of the research output, in terms of the potential introduction of bias into data collection, analysis and reporting.

Whilst these guidelines do not attempt to provide all of the answers, they draw attention to some of the challenging questions that need to be dealt with, to allow consideration of research practice and processes (often avoided), to be addressed within a framework that minimizes risk to both researcher and participant. Of particular value, is a section dedicated to the relationship between the ‘distress’ that might be experienced by participants being interviewed about sensitive issues and the ‘harm’ that must be avoided to comply with the duty of nonmaleficence in health research. Whilst there is no deviation from the principle-based ethics traditionally considered relevant to health research, the survivor researcher’s perception of harm and that of a health professional, with their associated responsibilities and accountabilities, may differ substantially. Similarly, a brief exploration of the limits of the confidentiality assured to participants, particularly outside of the framework of professional codes of conduct and where the research subject is particularly sensitive or contentious is worthy of consideration.

One of the main benefits to be derived from these guidelines is that if used as a framework, it should steer a research team to, and in some instances through, the debates they need to have, to reach agreement about their position in relation to ethical dilemmas that might arise during the course of the research process.

It is not surprising, given the nature of the consultation that informed these guidelines, that greatest emphasis is placed on the impact of ethical issues on individuals engaged in survivor research. However, it is disappointing that similar importance is not given to the potential impact and effect on the overall quality of the evidence provided by this method of research.

In this short text, the author makes good use of aids such as checklists, summary boxes and direct quotes to illustrate points, which make an interesting as well as informative read. Where appropriate, such as in the issues of appropriate payment of survivor researchers and where other comprehensive guidance exists, references to other sources of information and training resources are given.

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**Smyth, M. and Williamson, E. (eds)** 2004. *Researchers and their 'subjects': Ethics, power, knowledge and consent*. Bristol: Policy Press. 240 pp. £23.00 paper. ISBN 1-86134-514-3, £50 cloth. ISBN 1-8613-451-5.

This highly engaging and accessible book should be essential reading for health care researchers concerned for their 'subjects' well-being, as well as the bodies that fund research and those whose role is to ensure clarity and rigour within the research governance and ethical review process. Sections I and II, in particular, offer the reader a detailed, critical analysis of the ethical and governance process, often with input from those human 'subjects' who find themselves involved in research projects – a perspective which, as the editors point out, is usually missing or overlooked in research and

the reporting of research findings. The book is also unusual in that it transcends social science and natural/medical science boundaries, highlighting where similarities, or, more often, differences, exist in the respective ethics and research governance procedures. This volume manages with great effectiveness to juxtapose the experiences of researchers and the 'researched' from areas within health, medicine, medical ethics, journalism, social policy and women's studies.

Section I features four chapters on participation and inclusion which raise issues of power, transparency, consent, honesty, confidentiality and safety by exploring the involvement of four diverse populations in research – mental health service users, oncology patients, children, and people with learning difficulties. The writers of two of these chapters outline how their 'subjects' (mental health service users and people with learning difficulties) were involved from the very beginning – in terms of helping to define the 'problem' to be researched, the approaches that could be taken to understand the 'problem' and research field work. Anyone who has a desire to involve their participants fully in the research process or, who needs to assess research protocols that include such an approach, would benefit from reading these chapters, all of which eloquently illustrate some of the many events that even an experienced researcher may fail to prepare for. The other two chapters on participation and inclusion are also effective at forcing researchers and research assessors to consider how participants feel about being the subject of research and what 'choice' they perceive they have when deciding whether to participate. It is striking that the 9–11 year-olds enrolled in a longitudinal, epidemiological study rationalized their decision-making processes in similar ways to the adult oncology patients asked to participate in a randomized control trial. What is less reassuring is that the children sometimes said they would prefer not to take part in all the activities associated with the research, but felt too embarrassed to say why.

Whilst research governance and ethical review have become essential elements of planning a research project, many researchers have become frustrated at some of the conditions placed on their research by local research ethics committees (LRECs) – particularly when the research is at the interface of medical and social disciplines and when the health care or treatment of participants

is unlikely to be affected by the research process. Section II contains two well-written chapters, which explore factors that influenced the ethical review procedure, which in turn had an impact on the research process itself. Both research projects described in these chapters involved health service users – psychiatric patients and patients aged 80+ identified via the lists of two general practitioner (GP) practices. Sarah Nelson, in her study of women with mental health problems who were survivors of childhood sexual abuse, persuasively argues that the issues which members of the LREC were concerned about (opening a ‘can of worms’ being the core issue of contention) were at odds with the needs of the women who were often desperate to tell of their experiences and not to have their childhood abuse ignored by health professionals. Similarly, the other chapter in this section describes how members of the LREC were concerned about the inclusion of older people with dementia in research when the research team were concerned that the experiences of *all* older people be represented in their findings, not just those in good mental health. The authors of both these chapters are able to reflect on their experiences

with LRECs and use these (often negative) experiences to improve their research. Sarah Nelson’s conclusion, however, that the relationship between nonmedical researchers and the (mainly) medical representatives serving on LRECs needs to be addressed to ensure that the ethical review process does what it set out to do – to protect the rights and dignity of research participants.

The final section was rather disappointing after the thought-provoking 120 pages of Sections I and II. Here the aim was to further illustrate the issues, which affect the researcher/researched relationship, through five further chapters written from different knowledge paradigms (journalism, research activism, epidemiology and social science). These chapters, however, seem superfluous and repetitious, though I have no doubt they are just as well written and, in a different volume, would add to the research ethics/knowledge debate.

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