

Dear Editor

The paper 'Ethical Issues in Research With Vulnerable Populations' by Douglass and McCabe (Volume 6, Number 3) made interesting reading and it was pleasing to see due credit given to the Cartwright Inquiry and Cartwright Report in providing a spur to the development of bioethics in New Zealand and in leading to a major revamp of ethics committees in New Zealand.

However, one aspect disturbs me. The revelations of 'the unfortunate experiment' and the Cartwright Inquiry did not happen as night follows day. And it was not axiomatic that the Cartwright Report of 1988 would provide such a valuable blueprint for ethics in New Zealand. Neither was it a foregone conclusion that the report would be implemented.

This paper, in common with most reports over the past decade, overlooks or minimises the contribution of a women's advocacy group, Fertility Action (now Women's Health Action), under whose banner Phillida Bunkle and I, founders of the group, brought to light and pursued this issue at considerable risk and cost to ourselves.

The original *Metro* article (presented to the inquiry in its unedited form) discussed what happened to patients within the context of ethical issues such as the ethics of research, patients' rights and informed consent. We then had to fight hard to ensure that the inquiry followed these revelations. Believe me, there were powerful medical interests who worked hard to try and prevent that. Once the inquiry was established, we sought and were granted party status. We appointed experienced counsel and participated in every sitting of the inquiry. Fertility Action's counsel led the cross-examination and raised many of the issues that became key aspects of the report. For example, we analysed and reviewed the minutes of the National Women's Hospital Ethics Committee over a number of years, demonstrating serious deficiencies in its processes and performance. Our final submis-

sions were extensive and argued for patient advocates and a health commissioner – arguments that were accepted by the judge. Since the report, Women's Health Action has tirelessly lobbied to ensure that the recommendations were implemented. We commemorate the release date every year and in this year – the tenth since its release – plan a major review of how complete the implementation is.

I am outlining this to explain why it is so disappointing to see our contribution overlooked. This is not said for the purpose of seeking personal accolades but because the omission writes community activism and feminism out of the story. Without wishing to minimise the contribution of other parties, the progress that has occurred is a direct result of advocacy by a community-based consumer lobby group, led by feminists. Other women's groups have also assiduously supported the implementation of the reforms, often in the face of extreme inertia and reluctance on the part of those with the power to implement the report. The first five years of this effort is outlined in Women's Health Action's book, *Unfinished Business* (1993), so it is well documented, and our newsletter *Women's Health Watch* has continually reported on our battles on public access to ethics committees, the Health Commissioner legislation, and so on.

This is ongoing. Recent issues have been: making sure the Special Duty women were not charged out-patient charges when they visited National Women's Hospital, submissions on the future of ethics committees in New Zealand, and the progress of the review of the cases of National Women's patients with a diagnosis of dysplasia that Judge Cartwright recommended. We continually raise the issue of ethics and managed care and the implications for the doctor/patient relationship and informed consent.

The Douglass and McCabe paper speaks of the concept of partnership implicit in the Treaty of Waitangi and

says that an awareness of Maori cultural needs was another outcome of the Cartwright Report. They advocate the continuation of relationship building between Maori communities and researchers.

We applaud that, but ask why that concept of partnership has not been applied to a group such as ours and other organised women's health consumer advocacy groups who have shown a vital interest in ethical issues. In the immediate aftermath of the inquiry, universities and other agencies made some attempts to work with consumers but this effort has gradually evaporated.

Our recent experience is that we have been side-lined and ignored. Increasingly organised health consumer groups are denigrated as 'professional consumers' and inexperienced 'lay' people are preferred as the public voice. We are challenged as to our mandate to speak for consumers. We are seen as 'trouble-makers', with scant acknowledgment that trouble sometimes has to be made, as in the case of 'the unfortunate experiment'.

Ethics have become the preserve of universities and professionals. We are rarely asked to take part in conferences, workshops or other processes on health sector ethics.

Phillida and my work has simply become a citation on the end of someone else's paper.

Perhaps in this tenth year since the Cartwright Report an attempt could be made to inaugurate a true partnership between organised representatives of communities, professionals and policy-makers, in the true spirit of Cartwright.

Yours sincerely,

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