

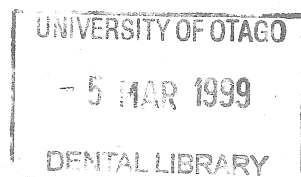


## Guest Editorial

### What are the Implications of the Changing Roles of Ethics Committees?

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#### Introduction

Ethics committees in the health sector in New Zealand have variously been charged, since 1973, with reviewing research, innovative treatment, treatment protocols and health care delivery. The recent review of regional ethics committees looked at committee structures without considering function. Yet the remit for ethics committees in New Zealand is very broad and it is almost certain that they are not fulfilling it. Where did such a broad remit come from, why were some of these tasks ever considered appropriate for an ethics committee, and what are the options for ensuring these tasks are done in the future?

#### Research and Innovative Treatment

Research and innovative treatment have been considered together ever since ethics committees were first formally instituted in New Zealand. An important reason for the setting up of the first committee at Auckland Hospital in 1973 was the use of unorthodox and secret cancer therapies at the hospital by Milan Brych.<sup>1</sup> Later, Judge Cartwright also concluded that the same ethical standards should apply to new treatments as to experimental research.<sup>2</sup> The Auckland Hospital Board guidelines formed part of the basis for the Department of Health National Standard for ethics committees which was released following the Cartwright Report in 1988.<sup>3</sup>

#### Treatment Protocols

Treatment protocols fell under the remit of ethics committees between 1988 and 1991. Judge Cartwright recommended that treatment protocols be developed and maintained for gynaecological conditions and that significant shifts in treatment of gynaecological malignancy should receive both ethical and scientific assessment.

The purposes of treatment protocols included developing a joint approach by all specialists involved in the management of a condition and as a basis for providing information to patients. She recommended that they be the responsibility of the hospital medical committee. When they were included in the first National Standard in 1988, clinicians objected that ethics committees were the wrong groups to assess them, because only peers working in the field were likely to have enough knowledge for this assessment.<sup>4</sup> It is likely that the lay chairpersons of ethics committees agreed, as in their revision of the Standard in 1991, treatment protocols disappeared from the remit.<sup>5</sup> Although ethics committees are no longer responsible, treatment protocols have not disappeared altogether. National protocols for the management of women with abnormal smears have continued to be produced regularly since 1989. The National Health Committee's guidelines development project can be seen as a similar exercise. Although not subject to formal ethical review, guidelines have been published and hence

have been available for professional and public scrutiny.

### Health Care Delivery

In 1991 the National Standard expanded the functions of ethics committees to include "any matter of ethics relevant to health care delivery". In 1993, following the health reforms, an interim task group was set up to advise on the transfer of ethics committees from Area Health Boards. The ethics committee chairpersons' submission concentrated on health care delivery issues and stressed the need to retain a consumer voice in the new system and the need for ethical review at multiple levels in the reformed system. The task group recommended the establishment of a National Advisory Committee on Health and Disability Services Ethics. Health care delivery issues were also retained in the revised 1996 National Standard.<sup>6</sup> The national committee might have been expected to advise the Minister on the ethics of new health policy initiatives, but the Minister has not sought its advice. Practical issues in the ethics of health care delivery might also have been addressed at the regional level, but there have been difficulties, as shown by the Stent report into Canterbury Health.<sup>7</sup> Moreover, some regional ethics committees have not addressed such issues at all.

### Implications

Research and innovative treatment should continue to be considered together, by the same committees. But the attempt to insert ethical review at multiple levels into the reformed health system needs to be re-thought. The primary motive was probably to retain a public voice in a system devoid of input from elected representatives, but it didn't work. Arguably it shouldn't have worked, as ethics committees have no public mandate to decide national or local health policy. Right now very troubling decisions are being taken by the Health Funding Authority. A method of prioritizing health services according to a principle which would decide "equity" according to the health outcome for groups is being contemplated. This could leave health services with no obligation to provide care to all individuals on the basis of need, as has existed – at least implicitly – until now. This is a major political issue and shouldn't be decided behind closed doors by economists or even ethicists. Similarly, at a regional level, ethics committees were in no position to stop the disastrous management practices which have afflicted hospitals in Christchurch and Dunedin and elsewhere since the reforms. Elected representation on health boards is a more power-

ful way of retaining a consumer voice. Then separate committees on health care ethics operating close to local services could make an appropriate contribution.

### References

- <sup>1</sup> Richmond, D.E. Auckland Hospital ethical committee: the first three years. *NZ Med J* 1977; 86: 10-12.
- <sup>2</sup> Cartwright, S.R. *The report of the cervical cancer inquiry*. Auckland: Government Printing Office, 1988, p. 152.
- <sup>3</sup> Department of Health. *Standard for ethical committees established to review research and treatment protocols*. Wellington: Dept of Health circular memorandum, 1988.
- <sup>4</sup> Harvey, V., Evans, B. Research and patient care: what needs review and by whom? *NZ Med J* 1989; 102: 229.
- <sup>5</sup> Department of Health. *Standard for ethics committees established to review research and ethical aspects of health care*. Wellington: Department of Health, 1991.
- <sup>6</sup> National Advisory Committee on Health and Disability Services Ethics. *National standard for ethics committees*. Wellington: Ministry of Health, 1996.
- <sup>7</sup> Health and Disability Commissioner. *Canterbury Health Ltd*. Auckland: Health and Disability Commissioner, 1998, pp. 115-8.

## Interview with Barbara Nicholas

*Barbara has accepted a new position with the New Zealand Technology Assessment Clearing House which is part of the Department of General Practice and Public Health at the Christchurch Clinical School. In this interview Barbara reflects on seven years with the Bioethics Centre.*

**OBR:** What have you enjoyed most about working at the Bioethics Centre?

**BN:** The highlight of working in the Centre has to be the chance to work with such a diversity of people. There have been some absolutely wonderful students who have come through the Bioethics Centre, with vast life experience and lived wisdom which they bring to class and to conversations between class. I've really enjoyed working with a variety of people around the medical school and across

the university and being involved in interdisciplinary projects. And I've really enjoyed working with people around the country, on organisations such as the National Ethics Committee on Assisted Human Reproduction and the Health Research Council ethics committee, doing workshops with community groups, and being part of planning bioethics conferences. I have met so many amazing people who are involved in ethics. This is, I think, one of the very distinctive things about New Zealand ethics – we have such a breadth of people involved. Ethics hasn't become something that only the experts can contribute to, but a series of conversations where an enormous range of people can contribute to policy and practice and to the thinking through of new challenges.

For me, the exciting thing about working in bioethics is that it is so interdisciplinary. Every time I have a conversation with people they are asking different questions and looking at things in a different way, so it is almost impossible to get stuck with one interpretation. There is always the challenge of needing to think about things differently and engaging in fresh questions.

**OBR:** What have you done that you feel most pleased or excited about while at the Bioethics Centre?

**BN:** The teaching has been a highlight. I've been involved in establishing some of the new courses for both the Masters and the undergraduate programmes.

*This interview is continued on pages 7 and 16.*