

## FROM THE EDITOR'S DESK

**Indigenous Peoples and Medical Research**

Two articles in this issue of the *New Zealand Bioethics Journal* consider guidelines for medical research involving indigenous populations in Australia. The articles are complementary. Kim Humphery considers the history of the guidelines which Ian Anderson *et al.* put under the spotlight. The commentary by Andrew Sporle highlights and reflects briefly on some of the issues raised by the two articles, partly in the New Zealand context.

The existence of the guidelines which are the subject of these pieces draws attention to the growing significance of the concerns of indigenous peoples to the process and aims of medical research. In some ways this parallels the concern for the wellbeing of the individual research participant which characterises many research guidelines. But where guidelines protect the collective interests of a group this adds a significant dimension.

Starting with the Nuremburg Declaration, the central and more or less universally accepted ethical value in medical research is that of participant consent. Admittedly, consent of participants is not sufficient to guarantee ethical research: in some cases the potential harm of a protocol may be such that an ethics committee may take the view that no one should even be asked if they wish to take part. Moreover, an ethics committee will wish to ask questions of the science of the research, such as is a trial organised in such a way that it can achieve its stated aim. But, in many cases, consent is an, or the, essential element of the protection of the individual research subject.

But the concerns of indigenous peoples may go beyond the

right of individuals to consent or refuse consent to medical research. Broadly speaking, in individual consent, a protocol formulated by researchers is presented to the prospective participant whose role is to decide whether or not to participate. The individual is not invited to take part in formulating the research protocol, or indicate avenues of research for the future. There is a passivity to the participant's role. But in some cases indigenous people are demanding a greater say in the research agenda, insisting, for example, that the benefit or potential value to a particular group be considered in the framing of research.

The significant thing is that indigenous people form a group (or groups) within society. To guard the individual rights of members of these groups is of course important, but the rights of the group within society are also at stake. The relation of medicine to groups within the population has historically been problematic. The events Judge Cartwright enquired into have been seen as involving the exploitation of women, and the Tuskegee natural history of syphilis trial rested on the exploitation of poor black men. The biomedical research establishment was perceived as having a culture at least in part characterised or influenced by attitudes – sexist or racist – which led to these events.

Guidelines on research involving indigenous peoples such as those discussed by Humphery and Anderson *et al.* act as a vehicle for protection against such attitudes. But they can also be a vehicle for a more active involvement of indigenous peoples in research design and planning, thereby minimising risks of harms and maximising opportunities for benefits. In this way, the guidelines may influence the development of a collaborative model of medical (and scientific) research generally.