

FROM THE EDITOR'S DESK

Technological advances in the early detection of disease, and developments in epidemiological knowledge mean that it is possible for population-based screening for a number of conditions to be carried out. Mass screening of a population is undertaken to detect those few who suffer from a particular health problem in order to effect a change in the course of a disease process. The introduction of a population based screening programme raises some important ethical concerns, which come from a number of sources. The first of these emerges from the high cost of screening a large number of the population, and the time and inconvenience for the population being screened. There is an ethical responsibility to ensure that scarce resources are used effectively and participants in the screening programme are not wasting their time.

There is also the potential for harms from a screening programme. False negative results (when the test indicates people screened do not have the condition, when they actually do), can lead to false reassurance and possible unchecked progression of the disease. False positive results (when people are told they have a condition they do not) may lead to avoidable anxiety and possibly further unnecessary interventions. Costs to society and the individual, and the potential harms that can arise, mean that there is an ethical obligation to ensure that the screening programme to be introduced is properly organised, effective, well monitored, and is able to provide the benefits asserted.

In order for effective monitoring and evaluation of a screening programme, public health doctors (auditors) will need to have access to test results and to follow up those found to have the disease. Getting individual consent in order to audit may not be possible, desirable or practicable. Proceeding with auditing without consent raises the issue of whether individual autonomy and privacy concerns could or should be outweighed by societal interests.

The National Cervical Screening Programme (NCSP) (set up following the Cartwright Report) was implemented without adequate provision for monitoring and evaluation, despite the fact that international guidelines for the establishment of cervical screening programmes were available at the time (Richardson, 2001). Without adequate mechanisms in place to ensure the effectiveness of the screening programme, errors in reporting and underdiagnosis such as those encountered at a Gisborne laboratory, could continue unchecked. An audit of the programme by public health doctors was proposed in 1999 but was withdrawn after ethics committees raised privacy and consent concerns and asked for amendments to the study.

An Inquiry undertaken into events surrounding the Gisborne laboratory misreading of smears in 2000 closely examined the ethical and legal issues related to evaluation of the screening programme. The Inquiry reported that 'by far the most important change which is required to make the National Cervical Screening Programme fully effective is the removal of legal barriers which are preventing the comprehensive evaluation of the Programme from proceeding' (Ministry of Health, 2001, p.1). The Minister of Health proposed changes to the 'legal barriers' in June of this year. These changes will enable auditors access without consent to identifiable health information of women who have developed cervical cancer, including their NCSP records, laboratory slides and the clinical records held by the woman's doctor, nurse, specialist or hospital. Cancer researchers will be able to access information from the NCSP Register, but may

need approval from an ethics committee for further research (Ministry of Health, 2001, p.5).

It is the access by auditors to the clinical records held by the woman's doctor, nurse, specialist or hospital without the woman's consent that is probably the most contentious. These records may contain a great deal of personal information of no relevance to the auditor's task. Women may not feel comfortable with this even though there are requirements on auditors to maintain confidentiality. This concern is understandable, and yet on the other hand, if auditors cannot access the material they need, then they cannot confirm that the screening programme implemented is accomplishing what it sets out to do, as well as preventing debacles such as arose in Gisborne. Some authors believe that we all have a moral duty to participate in audit, based on our duty to prevent harm to others, to assist others, and because it is fair that we, as patients, all contribute to a service from which we gain benefit (Barrow, Hagger and Woods, 2001). The authors go on to state that: 'this claim does not diminish the moral importance of each individual patient nor does it give licence to health professionals to pursue their audit interests without due consideration to their moral and legal responsibilities' (Barrow, Hagger and Woods, 2001). However, given the proposed changes to New Zealand legislation that requires release of the full health records of women without consent, there is concern that auditors will not bother obtaining consent even if it is both practicable and desirable. In this instance, auditors may have met their legal responsibility but not their moral responsibility, because the legal obligations have been set too low.

Commentators are already claiming that these changes are a step too far, and that they will undermine current legislation regarding patient rights and privacy (Coney, 2001; McLeod, 2001). If women become concerned that their personal health information is now too accessible to others, the consequence may be that they will opt off the screening programme, and may cease having regular cervical smears.

A balance is clearly required between respect for privacy and pursuit of public good. To achieve this balance further academic discussion and public debate will be essential.

In this issue of the journal, we are fortunate to have an article by Helen Davidson, John Dawson and Andrew Moore that explores the legal and ethical aspects relating to the proposed audit of the New Zealand National Cervical Screening Programme.

References

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