

## Editorial

# Medical research needs lay involvement

Tony Hope *Editorial Associate, Journal of Medical Ethics*

Today's research is tomorrow's medicine. Battista (1993)<sup>1</sup> described patient-centred medicine as a Copernican revolution. If this revolution is to become a reality then patients will need good quality evidence, relevant to their interests and values so that they can make their own choices.<sup>2</sup> Today's research must provide that evidence. Harper, in this issue of the journal,<sup>3</sup> gives examples where the reporting of research fails to allow for variations in patients' values. His examples concern the question of medical futility, a key concept in decisions about resuscitation.

One of the first patients I met, during my first surgical attachment as a clinical student, was a man dying from carcinoma of the pancreas. My fellow students and I were shocked to discover that this patient did not know his diagnosis; nor was he aware of the severity of his condition. When we raised this issue, somewhat diffidently, with the consultant surgeon, he told us that it would be unfair to burden the patient with such knowledge. "It would only upset him," he said. Few of this surgeon's patients with cancer knew their diagnosis. Twenty years later such a paternalistic attitude is rare.

I am reminded of this change in practice every time I discuss the question of patient involvement in decisions about resuscitation. Doctors often avoid talking about resuscitation with patients for fear of worrying them unduly. In twenty years' time, I suspect, this will sound as old-fashioned as does my former consultant's practice of not telling his patients when they were dying.

A central reason for deciding that a patient is not for resuscitation is that such treatment would be medically futile. There are two possible meanings of futile. The first is that the benefit is not worth the cost. Some worthwhile treatments cannot be provided within the health care resources available. Resuscitation can be expensive; for example if it leads to admission to an intensive care unit. However, the term futile should not be used as a surreptitious way of limiting resources. The second meaning of futile implies that the intervention (resuscitation) will not work. The lit-

eral meaning of this is that there is zero chance of a worthwhile outcome. Nothing in medicine has zero chance, and what is a worthwhile outcome will differ for different people. In twenty years' time, I predict, it will be routine for patients to be involved in deciding the question of futility. In order to do this, patients will want to know the chance of three broad outcomes: useful survival; survival that is worse than death; and useless survival. Different patients will have different views on what is or is not useful survival. In order to find the necessary information, patients and their doctors will need to turn to research. What will they find? They will find the results of many studies. These studies will give the outcomes of resuscitation in a number of clinical situations. Typically the results are given by defining a number of outcome categories. One of these categories is "futile" survival—that is survival too short to be worthwhile for the patient. Most studies consider that resuscitation is futile if the patient does not live to be discharged from hospital.

Harper argues that for some patients, in some situations, short periods of survival without discharge from hospital may be worthwhile. Such patients will want to know the chance of survival for short periods in order to decide whether they wish to be resuscitated. However, the published research will not provide the evidence they need. This is because survival without discharge from hospital is placed in a single category: futile.

Patient-centred medicine is, in part, a reaction against doctors making value judgments on behalf of their patients. Harper draws attention to what might be called "patient-centred research"—a reaction against researchers making value judgments on behalf of future patients. Harper focuses on the reporting of outcome data. His point, however, is just one example of a much broader issue: the role of lay people in the whole process of medical research.

Entwistle and colleagues<sup>4</sup> have recently argued for the importance of lay involvement in medical research on two grounds: first for democratic reasons. The public pays for much research and

therefore has a right to a say in what research is carried out. Furthermore the purpose of medical research is the good of patients in the future. The second reason they give for the importance of involving lay people in medical research is to improve the quality of the research by ensuring that it addresses questions important to patients, in a way likely to be of most benefit to them.

Oliver,<sup>5</sup> and Entwistle and colleagues<sup>4</sup> have identified several stages in the research process at which lay involvement may be useful. These include: deciding on priorities for areas of research; choosing the research to be funded within the priority areas; identifying problems and formulating research questions; designing the research project; project execution; interpretation of the findings, and interpretation of the findings from many research projects (as in systematic reviews). Entwistle and colleagues also suggest a number of different categories of people who can give a lay perspective. For example: patients and former patients; carers; potential users of specific health services (for example, pregnant women), and organisations that represent patient groups or lay people.

There are a few examples of areas of research where the lay perspective has had a major impact, for example in pregnancy and childbirth, and in HIV infection. These areas provide a model for the further extension of lay involvement. Chalmers<sup>6</sup> gives a number of specific examples in the field of pregnancy and childbirth. Lay people have identified important research questions: it was a mother of a child with trisomy 18 who first suggested that serum  $\alpha$  fetoprotein levels might be a prenatal marker for this chromosome abnormality. Lay people have a particularly important role in identifying the outcomes that the research should assess—outcomes that are important to patients. Lay people were invited by researchers to comment on a protocol for a trial of low-dose aspirin. The purpose of the trial was to assess whether aspirin taken during pregnancy would reduce problems associated with hypertension. The lay people were concerned that there were no plans to assess the babies, who could be damaged

by the aspirin. This concern is likely to be a key issue for patients. Lay people have also been involved in the research process itself, helping to design information leaflets and aiding recruitment.

In the UK the Department of Health has taken a lead in formally recognising the potential importance of lay involvement in research. A Standing Advisory Group on Consumer Involvement in the NHS R&D programme was set up in 1996. This committee is chaired by Ruth Evans, director of the National Consumer Council. It aims to find constructive ways in which lay people can be increasingly involved at all stages of the research process.

The presocratic philosopher, Xenophanes of Colophon, wrote: "... in the course of time, through seeking we may learn, and know things better . . . . But as for certain truth, no man has known it, nor will he know it . . . . For all is but a woven web of guesses."<sup>7</sup> Medical researchers seek truth, but their perspectives alone are not enough. Lay perspectives are a necessary ingredient of the "woven web of guesses" which constitutes medical knowledge.

*Tony Hope is Editorial Associate of the Journal of Medical Ethics, a Psychiatrist and Reader in Medicine and Leader, Oxford Practice Skills Project, Oxford University, UK.*

## References

- 1 Battista R. Practice guidelines for preventative care: the Canadian experience. *British Journal of General Practice* 1993; **43**: 310-4.
- 2 Hope T. *Evidence-based patient choice*. London: King's and Co., 1996.
- 3 Harper W. The role of utility judgments in improperly limiting the scope of clinical research. *Journal of Medical Ethics* 1998; **24**:308-13.
- 4 Entwistle VA, Renfrew MJ, Yearley S, Forrester J, Lamont T. Lay perspectives: advantages for health research. *British Medical Journal* 1998; **316**: 463-6.
- 5 Oliver SR. How can health service users contribute to the NHS research and development programme? *British Medical Journal* 1995; **310**: 1318-20.
- 6 Chalmers I. What do I want from health research and researchers when I am a patient? *British Medical Journal* 1995; **310**: 1315-18.
- 7 Quoted in Popper KR. *Conjectures and refutations: the growth of scientific knowledge*. London: Routledge and Kegan Paul: 1959: 3. Also see reference 6 where it is partially quoted.

J Med Ethics 1998; 13: 292-293. Downloaded from <http://medeth.oxfordjournals.org/> by guest. Protected by copyright.