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The controlling interests of research

The costs of medical research have increased to levels that even the wealthiest universities can no longer afford. Private industry, driven by the public's appetite for innovation, has begun to assume the lion's share of those costs, and a formidable share of control. The boundaries between new science and applicable technologies, and hence between knowledge as a good and knowledge as a commodity, have become blurred.^{1,2}

Some argue that the marriage of academic research with private funding will be repented: the incompatibility of commercial and scientific goals is so profound, they caution, that control over virtually all research into human health should be restored to the academy.³ Others, particularly those working in technologically intensive fields such as genomic and phenotypic research, argue that public funds cannot do the job. We must have partnerships, but we have to manage them better.⁴

We take the latter view, not because resistance is futile (it may be), but because partnerships with industry have been beneficial. But these partnerships must be carefully structured to protect the rights of research subjects and the intellectual freedom of scientists. Participants in clinical trials have a right to be fully and continuously informed of their risks, and their participation should never be rendered valueless by the distortion or suppression of results to satisfy commercial goals. As for the right of investigators to unobstructed inquiry and publication of results — this is a core value not only of scientists but also of society as a whole.5

Are problems of data suppression and inadequately informed consent common or, as in Nancy Olivieri's research relationship with Apotex, spectacular but rare? A recent survey of 108 medical schools in the United States reveals that very few agreements between academic medical research sites and their industrial sponsors adequately protect investigator independence. Median scores for compliance with such essential items as ensuring that the investigators had ac-

cess to all the data in a multicentre trial were astounding. Only 1% of the site researchers surveyed had access to all data in the trial, and only 40% had control over publication of their findings. These scores confirm the worst fears of the International Committee of Medical Journal Editors, who last year announced ethical eligibility criteria for the publication of trial results.⁸

Is the situation in Canada similar? To find out, we should replicate the US study. We should also survey our universities to determine how they advise and supervise academic staff and students who have direct financial ties with the sponsors of their research. Perhaps, in the model of Harvard and the University of Pennsylvania, our universities can be encouraged to proscribe personal financial ties between investigators and industry.

Most of all, we need national leadership and perhaps even a national organization to promote and monitor ethical behaviour in research. We need unequivocal standards to protect the rights of patients involved in research and to honour society's need for unimpeded scientific inquiry and dissemination of results. — CMA7

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