



are also some good Canadian studies. A literature search for the past 2 years in the MEDLINE database, with the search terms "depression" and "stroke" and "rehabilitation," yielded 241 articles. Of these, some examined patients' access to effective services,<sup>4</sup> and others showed clear correlations between functional impairment and depressive symptoms.<sup>5,6</sup> Many presented in more detail the impact of depression on recovery,<sup>7,8</sup> and others showed that depressive symptoms and illness behaviour can assist in predicting response to rehabilitation.<sup>9,10</sup> There is clear evidence that active interventions reduce the incidence of depression among stroke survivors.<sup>8</sup>

This wealth of information indicates that this topic deserves our attention, especially given that we Canadian physicians already know how to treat depression. A single reference to the psychosocial impact of stroke on caregivers in the *CMAJ* editorial<sup>1</sup> seems inadequate to capture the breadth and depth of this area.

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## Does the CMA's privacy code go too far? Or far enough?

As an observational researcher, I am disturbed by the CMA's Health Information Privacy Code<sup>1</sup> and fear that it will unduly constrain legitimate research. It appears that the developers of the code failed to distinguish 2 very different uses of patient information. With the first, a third party, such as an insurer, is interested in the patient as an individual, and its use of medical information could have a direct impact on the social and economic life of that patient. With the second, a third-party researcher is interested in the patient as a member of the human species. This observational researcher hopes that the patient is representative of other humans with similar characteristics, such as age, blood pressure or blood-sugar level, and hopes to generalize data from that individual to the species. For most observational research, individual identifiers are irrelevant and could be stripped from the record after all relevant information has been gathered. I firmly believe that the potential benefits to society of observational research greatly outweigh any hypothetical harm that access to personal information might entail.

I am currently trying to link an occupational cohort of some 21 000 people with records from the Ontario Cancer Registry to search for associa-

tions with exposure to a putative carcinogen. Research of this kind has been responsible for the identification of most known human carcinogens.

Now, a member of the university ethics board has asked me to obtain individual consent from all 21 000 members of the cohort and to offer each one the chance to have his or her name removed. Tracing and contacting each subject would be prohibitively expensive, and allowing individuals to withdraw would render the study results uninterpretable because of the possibility that the decision not to participate was correlated with the outcome of interest.

I urge the CMA to reconsider the implications of its Health Information Privacy Code and to recognize the difference between these 2 uses of patient information.

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## Reference

1. Health Information Privacy Code [CMA policy summary]. *CMAJ* 1998;159(8):997-1006.

A patient of mine suffered soft-tissue injury to her neck and back in a motor-vehicle accident. She signed the consent for release of medical information at the Insurance Corporation of British Columbia (ICBC). When I received the request for photocopies of clinical records and a medicolegal letter outlining her injuries and treatment, I called her. When she realized that information about her abortions was included in her medical records, she refused permission for me to forward this information, despite having signed the ICBC release. But when



she arrived at the “examination for discovery,” it became clear that the ICBC lawyer had obtained the information about the abortions through another source (billing data from the provincial medical plan). The lawyer asked her about the procedures in great detail, until she was in tears and asked to be excused. She ended up settling the claim for much less than she or her lawyer had expected.

This experience was very traumatic for the woman. Clearly, she had not been properly informed about what the consent for release of information meant. Unfortunately, government billing information can be used by insurance agencies for “fishing expeditions” like this one, whereby they try to discover irrelevant information. In this case, such

information proved beneficial to the insurance company.

I’m worried that the CMA’s new CMA’s Health Information Privacy Code<sup>1</sup> doesn’t go far enough. As physicians, we must inform our patients what it means to release medical information. The way consent is obtained should be changed so that patients understand that when they grant it, information about any medical consultation or procedure involving any physician may be made available. They also need to know that they will not invalidate their insurance if they limit their consent to information related to the accident under investigation.

**Ellen Wiebe, MD**  
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1. Health Information Privacy Code [CMA policy summary]. *CMAJ* 1998;159(8):997-1006.

#### [The CMA president-elect responds:]

**D**r. Finkelstein’s belief that the CMA’s Health Information Privacy Code is a disturbing document is based at least in part on a misunderstanding. The code does not specify that individual consent is required for all research or for the type of research he discusses. Indeed, it explicitly anticipates the use of health information without consent for research purposes *under certain very strict conditions*.

The code also states that, given the importance of patient privacy and



consent, all nonconsensual secondary use of health information should be scrutinized carefully. The code itself does not undertake this; rather, it outlines considerations (a “legislative test”) relevant to such a review and promotes them. The code also indicates that a nonconsensual use deemed justified in light of such a review should be indicated in legislation, which makes it explicit and open to public scrutiny. (Survey and polling data show that the public is very concerned about the use of their health information without their consent, even for research purposes.) Given Finkelstein’s disagreement with the member of the ethics panel who requested that he seek consent and his confidence that his research should be permitted without consent,

he should agree with the importance of such a review and welcome the opportunity to debate the issues and clarify the rules.

Finkelstein is correct to distinguish between the use of health information for observational research and for purposes in which decisions about individual patients may be made. However, even though the former may be relatively benign compared with the latter, it still raises questions. The trend today is toward data linkages and the proliferation of databases. It is not clear how much patients, or their physicians for that matter, know about what happens to their health information in an increasingly computerized world and how they would feel about it if they did know.

The code is complicated enough

as it is, and rather than trying to settle the issues, it promotes explicit dialogue about them. The CMA hopes that this dialogue will engage not just researchers and health care professionals but also ordinary patients and the public in general.

I found Dr. Wiebe’s story disturbing, and it is precisely the kind of issue she raises that prompted the CMA to develop its privacy code. There is a considerable gap between the existing practices and rules for health information and the principles the new code espouses. Stating our principles is one thing, but implementing them is another. The CMA recognizes that a lot of work has to be done to implement the code, and the all-important first step is to create awareness. Our work receives a huge



boost when doctors such as Wiebe bring questionable practices to the attention of physicians and the public.

**Hugh Scully, MD**  
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## The myth of freedom from conflict of interest

The article by Trudo Lemmens and Peter Singer on conflict of interest<sup>1</sup> raises several important issues. However, rules governing conflict have created a slippery slope that has the potential to do harm. One of the most obvious examples is the attempt to separate the clinical researcher from the clinician, an approach that is counterintuitive to good patient care and continuity of care. Conflict guidelines have also created the false impression that a state of freedom from conflict could exist. However, such a state is impossible because of the nature of the physician-patient relationship, whereby physicians are paid for their services and decide for every patient the services to be offered.

My greatest concern, though, is the new fad of evidence-based review, which claims to be above conflict. Surely, if cost savings were not forthcoming, the drugs and procedures under review would cease to be funded by the governments that support health care. Yet it seems that as each new drug is taken along its evidence-based path, decisions are underpinned by the mandate to reduce costs and thereby secure future funding from the government sponsor.

The relationship among physicians, patients, industry and government is conflicted. Unless we admit this, we will be providing meaningless solutions to conflicts that are obvious or of media interest only, while failing to address the real issues.

We should define all potential conflicts, support disclosure and be very careful about regulating the path of individual professional conscience. In the end, the physician still has the personal responsibility to just do the right thing.

**Stephen L. Sacks, MD**  
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### [One of the authors responds:]

I agree with Dr. Sacks that conflicts of interest are an inherent part of medical practice. Indeed, we should not pretend that conflict-of-interest rules can create situations that are devoid of conflict. They also should not create unnecessary barriers between clinical care and research. However, I cannot see why conflict rules "have created a slippery slope," for example, by separating "the clinical researcher from the clinician."

Conflict-of-interest rules should help us to identify, for example, situations in which financial interests and research interests risk affecting clinical care. They should also provide an appropriate framework to deal with these existing tensions. The recent controversy surrounding Dr. Nancy Olivieri and Toronto's Hospital for Sick Children revealed that a lack of appropriate procedures to deal with conflicting interests can be counterproductive to both clinical care and research.<sup>1,2</sup> Reliance on individual conscience and mere disclosure of a conflict is clearly insufficient and lays too heavy a burden on physicians. Good conflict-of-interest guidelines help us to prevent situations that we know create serious risk of irremediable conflicts, and they give us a struc-

ture to deal with conflicts when they do arise. They also help physicians and the public to identify situations in which patient care and scientific integrity can be threatened, and they allow these groups to seek external support for tackling such issues. The increasing dependence on industry funding augments the potential for conflicts of interest and suggests the need for appropriate control.

As Sacks rightly points out, government interests can create similar tensions that are perhaps even more difficult to address. Finding an appropriate and transparent way to discuss and deal with conflicts in general should be high on the priority list of both physicians and government if we want to preserve public trust in medical research and clinical care.

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## Rehabilitation and stroke

I was initially pleased to see the supplement to the Sept. 22 issue of *CMAJ*,<sup>1</sup> which was devoted to the important subject of stroke and the evolution of its management. However, given that most people who have had a stroke of moderate or greater severity face a lifetime of altered functional abilities and difficulty in fulfilling their roles in society, I was surprised that the important subject of rehabili-