Consumers' Association of Canada (Alberta)

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Submission to Select Special Personal Information Act Review Committee
Legislative Assembly of Alberta

Dear Madame Chair and Members of the Committee:

Thank you for your invitation to participate in this review. We believe the challenges individual Albertans face related to both overt and surreptitious collection, use and misuse of their personal information are significant. There are equally significant challenges for individuals to ascertain the content and extent of information which other parties may be able to access about them; to understand how this information is used; to comprehend the ramifications of its use; to know what opportunities exist to protect themselves, and to understand who makes or enforces rules.

Increased computerization and reliance on the Internet for business and social transactions, time pressures, changes in the nature of the marketplace,[1] and the blurring of government and commercial activities and interests have all played a part in creating a new environment. It is also proving difficult for legislators to intervene effectively with direct regulation related to information use since the context is as important as specific activities; however, direct regulation is only one tool which governments have at their disposal to intervene in important societal issues.[2]

We have not prepared a detailed response to your Guide. Instead, we are requesting that you explore and address the gaps, overlaps, conflicts and inadequacies in federal and provincial legislation dealing with medical privacy and related fair information practices**.** For example, we have been advised that federal PIPEDA legislation over-rides the HIA and that PIPA has been declared substantially equivalent to PIPEDA; however, PIPA excludes personal health information, and PIPA and HIA do not deal with cross-jurisdictional information sharing.[3] Not only are individual Albertans being disadvantaged by this legislative morass: it has left them (and us) at a complete loss as to where to turn for help or to influence change.

This situation has taken on new urgency because of the growing presence and influence of commercial interests in the health care sector. These commercial interests are varied in nature. Major players include pharmaceutical and medical device companies such as Janssen-Ortho, Sanofi-Aventis and Depuy Inc. (Johnson & Johnson), and large dominant insurance companies such as Sun Life, Manulife, RBC and Great West Life. New health care broker, referral and case management companies such as Best Doctors and MedCan; independent imaging, surgical, rehab, and home care companies; and retail drug stores such as The Katz Group and Shoppers Drug Mart are on the front lines. Behind the scene are consulting companies such as AON, IBM and Milliman, drug trial companies, and a proliferating number of

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[1] Examples of the changing nature of the marketplace include increased reliance on fewer, larger and more distant suppliers, the use of "virtual" money, and the segmentation of customer classes and growth of "stealth" marketing based on customer profiling. These changes are tipping the balance of power in the marketplace and limiting the influence of consumers.

[2] Lawrence O. Gostin identifies seven tools which governments have at their disposal: the power to tax and spend, the power to alter the informational environment, the power to alter the built environment, the power to alter the socio-economic environment, direct regulation of persons or business, indirect regulation through the tort system and de-regulation of harmful laws or regulations.

[3] See more details at http://www.law.ualberta.ca/centres/hli/pdfs/ElectronicHealth.pdf

information management and market research companies such IMS, Rx Canada, Eyeforpharma and MIB. (Suggest "googling" names.) Many companies are vertically and horizontally integrated – and global. Of particular concern is the over-arching influence of pharmaceutical companies aimed at increasing sales.

A number of new privacy issues are emerging in this environment, including the lack of equal access to one's own health-related records in the face of increasingly routine access and use by so many other parties.[4] For example, in a presentation to the 2004 HIA Review Committee, a drug store group proposed that retail pharmacies be allowed to use their customers' health information for "monitoring therapy adherence", initiating reminders, and culling records to identify potential candidates for "wellness" initiatives such as diabetes and cholesterol testing and education events. Some Alberta and Saskatchewan pharmacies, as part of a study, have already used their customers' prescription records to identify possible "under-diagnosed" or "under-treated" customers and encourage them to come for in-store cholesterol testing and pharmacist management. We have been advised this model of customer surveillance and intervention, *clearly a marketing tool*, is considered one of the main benefits of recent legislation expanding the potential role of retail pharmacists and retail pharmacies in conjunction with their access to new on-line electronic health records.[5] Such paternalism is difficult to reconcile with most Albertans' notions of both medical confidentiality and patient autonomy. It is also difficult to reconcile with current controversies over growing evidence of harm from the increasing "medicalization" of normal, the use of surrogate markers to evaluate clinical benefits and outcomes, and the widespread promotion of questionable drug interventions.[6]

Another example relates to Canadians' increasing reliance on privately paid out-of-hospital services and products during a course of illness. This has led to greater dependence on commercial health insurance policies that are allowed to discriminate based on past medical history and lifestyle. The wording of required "release of information" forms, industry consolidation, and changing practices and relationships appear to put applicants at risk for everything from stealth marketing, identify theft and denial of claims to future denial of credit and employment.[7]

In summary, we feel the increasing commercial influences and marketing pressures in health care, combined with gaps, overlap and deficiencies in the current legislative landscape, significantly compromise Albertans – as patients, consumers and members of society. We respectfully request that your Committee explore this issue in your review. Even providing some clarity regarding existing legislation and current practices could help us all make more informed choices, limit harm, and encourage everyone to monitor and report problems to influence positive changes.

We wish you well in this important and challenging work. We also encourage you to visit the web sites identified in the footnotes for a fuller understanding of the issues.

Yours truly,
Wendy Armstrong
Member of the Executive (signature absent as sent by e-mail)

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[4] An overview of some of these issues can be found in handouts provided to the HIA Review Committee by our organization at www.albertaconsumers.org under News and Updates, September 2004.

[5] This includes new prescribing powers and the administration of injectables. See Leading Change in Pharmacy Practice, http://www.epicore.ualberta.ca/Leading%20Change%20FIP%2012-2004.pdf

[6] See "Selling Sickness" (Cassels and Moynihan) or http://www.diseasemongering.org/ and http://www.whp-apsf.ca/en/documents/doc_index.html , http://www.nybooks.com/articles/17244, http://www.abc.net.au/rn/healthreport/stories/2006/1735075.htm#transcript and http://www.slate.com/id/2150354/?nav=ais

[7] See "Reading the Fine Print" http://www2.m-thac.org/cgi-bin/WebObjects/mthac.woa pages 16/17 and attached example (PDF) of RBC form.