

Consumers' Association of Canada (Alberta)
(Consumers Association of Alberta)

**Response to Request for Submission to Advisory
Committee on Legislative Reform and
Alberta Health Act initiative**

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Consumers' Association of Canada (Alberta)
Box 11171 Edmonton T5M 0E4
(780) 426-3270
E-mail: contact@albertaconsomers.org
www.albertaconsomers.org

For queries about this submission, contact:
Wendy Armstrong, Chair, Health Committee
warmstrong@shaw.a

Table of Contents

- 1. Introduction**
- 2. Limitations**
 - 2.1 Missing context and information
 - 2.2 Lack of intervenor funding, time and resources
- 3. General Comments and Observations**
 - 3.1 Creation of an “enabling” Act limits legislative process and scrutiny
 - 3.2 Assumptions behind aligning decision-making with “intent” of the Act
 - 3.3 The need for public information, consideration and conversations
 - 3.4 Caveat on support for an entity to support evidence-based decisions
 - 3.5 The need for clarity of purpose and direction for the health system
- 4. Recommendations**
 - 4.1 Give Albertans the information they need to make informed decisions
 - 4.2 Give Albertans the tools to participate
- 5. Conclusion**

1. Introduction

The Consumers' Association of Canada was created in 1947 to provide a vehicle for "public engagement" and influence on policy, practices and regulatory decisions affecting the marketplace and public services. We are very aware of the economic, political, social and cultural factors that influence "the social determinants of health."

Our Association also has more than 60 years experience monitoring, researching, representing, informing, and protecting the consumer and citizen interest in relation to health care products and services, health research and health insurance. Over the last two decades, we have published a number of investigative reports on the changing landscape of health care in Alberta- available at www.albertaconsomers.org. We have participated in many provincial and national committees/consultations dealing with the challenges raised by an explosion of new medical and information technologies, the increasing commercialization of healthcare, the influence of the pharmaceutical industry on medical knowledge structures, and public perceptions about health and healthcare. In addition, our organization is familiar with the international trends, economic theories, jargon and global "consultant-speak" in health care that have wended their way around the world and found a permanent home in Alberta.

We believe our past and present work is relevant to any discussion of the future landscape of health care in Alberta. In particular, we refer to our 1989 *Consumer Rights in Relation to Health Care* document which describes the vital interests of citizens, including a *right to know* about the health care system, a *right to informed representation* in decisions influencing healthcare, and the *responsibility of citizens to consider the interests of other health care consumers*.

2. Limitations

Despite our interest in and concerns about these issues, however, we are unable to submit an in-depth brief in response to your request. There are two reasons; we have neither the necessary background information nor the resources.

2.1 Missing context and information

Context matters when it comes to answering the questions posed in your May 20, 2010 letter. Yet neither the Committee nor the Ministry of Health and Wellness has

provided the necessary context, clarity or detail for our organization to be able to provide “constructive analysis, input and discussion.”

The lack of context and detail contributes to skepticism on the part of the public and limits the potential for healthy debate. While you have stated that your mandate is to consult on the new Act and not what comes after, it is the “what comes after” that will affect the lives of some 3.7 million Albertans. One would not purchase an automobile without knowing “what comes after”.

It is difficult for Albertans to trust a process or engage in a constructive dialogue with little detail or access to analysis that would enable them to provide constructive comments and innovative ideas. Although we might hold differing perspectives, if we are to work collaboratively, sharing information and perspectives has the potential to develop a health care system that provides Albertans with the services they require, and a system they can support, having understood the options and choices.

For example, Primary Care Networks (or some version thereof) will likely figure prominently in future design of the Alberta healthcare system, yet we have been unable to obtain any information on an evaluation of this initiative although it has been in place since 2003.

Similarly, we have been met with a total lack of responsiveness in obtaining other information. Given the potential variations in the interpretation and application of principles, patients’ charters, and legislation and policy alignment with unclear and questionable goals and objectives, detail is critical.

It is difficult for Albertans not to be skeptical about future transparency and accountability when there has been so little with regards to this process.

2.2 Lack of intervenor funding, time and resources

Organizations representing the vital interests of citizens are at a great disadvantage compared to government, professional and industry groups when it comes to having enough human and financial resources on hand to respond to new demands on their time and resources. The assumption that the community has the capacity to respond to numerous and diverse requests for input does not recognize the current reality facing organizations. While there is a desire to provide informed analysis and input, the reality is that a significant withdrawal of federal and provincial grants and intervenor funding to support such work during the 1990s has limited the ability of organizations to respond. In short, our organization simply does not have the human and financial resources to provide an in-depth submission with six weeks’ notice.

3. Observations and Comments Based on Available Information

In the absence of both information and resources for in-depth analysis and response, we offer the following general comments and observations in relation to the *Foundation for Alberta's Health System* report and the questions in your letter:

3.1 Creation of an “enabling” Act limits legislative process and scrutiny

It appears that the creation of a single overarching and “enabling” Act will give the Cabinet or any entity delegated by the Cabinet (e.g. external organizations or individual administrators) the power and ability to make substantive changes outside the legislative process and public scrutiny. New undefined “public engagement” strategies with an undefined “public” would then *replace* (not augment) legislative scrutiny. We need both! In our view, the Cabinet already has too much discretionary power to change legislation through regulation. There have also been examples over the past decade where “public” representatives have been leaders in the industry under review.

3.2 Assumptions behind aligning decision-making with “intent” of the Act

The lack of detail and the many assumptions made about the desirability and feasibility of some of the identified pathways and goals and objectives or intent related to a) access; 2) research and technology; 3) optimizing the health workforce; 4) integration; and 5) engagement and incentives (pages 29-34), is troubling. There is no evidence in the document to support the basic assumptions.

3.3 The need for public information, consideration and conversations

Before decisions are made on a new legislative framework for healthcare legislation in Alberta, we believe there is a need for informed public conversations on:

- the nature and value of a “single-payer” model for core services;
- the intended and unintended consequences of a shift from designated in-house suppliers to “funding following the patient”, regardless of location;
- the options, benefits and costs of various models of continuing and primary care;
- the untoward effects of pay-for-performance incentives and overzealous performance measures on relationships, system costs and patient safety;

- the potential implications of the shift in language from equality to equity;
- the motive, content, process and applications of a patients' charter;
- the shift from professional practices to third party investor owned companies;
- the need for caution to limit harm around overzealous testing and prescribing;
- the need for controls over marketing and deceptive claims;
- the real drivers of healthcare costs and limits to prevention in curbing costs;
- the proliferating collection and secondary uses of personal health information;
- the multiple meanings of "patient-centred care"; and
- the potential negative impacts of "standardization" across service settings.

3.4 Caveat on support for an entity to support evidence-based decision-making

In light of your recommendation for an arm's length entity to support evidence based decision-making, there is an urgent need for discussion on the increased business orientation of universities. Our organization has long proposed and championed the creation of an academic-based provincial organization in Alberta similar to the Manitoba Health Policy Centre (ICES, CHSPR) and/or the Therapeutic Initiative in BC. These agencies serve the purposes of providing public access to information and analysis as well as supporting evidence-based decision making. Our support for such an entity is predicated on its structure, governance, funding and leadership and a pure public interest mandate.

3.5 The need for clarity of purpose and direction for the health system

We *strongly* share your view that "Alberta needs clarity of purpose and direction for the health system." We also *strongly* believe this clarity of purpose must come from informed public conversations about the competing agendas and philosophies that have influenced the nature and purpose of health care and health policy over the past two decades, including a policy shift in the early 1990s from patient care to "population health". All these changes and the use of jargon have left the public and many health professionals (and politicians) confused, bewildered and increasingly divided.

It's time to revisit this issue of purpose. This requires funds to support independent sources of information and real public engagement – and time.

4. Recommendations

Therefore, in order to begin the journey towards clarity of purpose and direction, we recommend:

RECOMMENDATION 1

Give Albertans the information they need to make informed decisions-

We recommend that the Alberta Legislature take advantage of the current review of the FOIP Act to improve access to information, including removal of current fee requirements.

We also recommend exploring changes to government policies and practices to open up communication with knowledgeable civil servants and representatives in delegated authorities and access to information without a FOIP request.

4.1 **RECOMMENDATION 2**

Give Albertans the tools to participate

We recommend that a method be developed for intervenor funding for organizations representing the vital interests of citizens as patient and consumers of health care services and products to enable these organizations to gain expertise and participate meaningfully in ongoing discussions, conduct independent research, respond to requests for input by policy-makers and help inform and engage the general public. (Restrictions should be placed on this funding for organizations also receiving direct or indirect funding from pharmaceutical companies.)

We also recommend exploring the creation of an independent source of funding for a provincial Health Care watchdog group to monitor activities in the healthcare sector and to undertake research and analysis and public dialogue in the collective interests of patients and consumers of health care products and services.

5. Conclusion

Albertans are intelligent and innovative. If we are to build a health care system based on collaboration and cooperation, we must be prepared to openly share information, listen to and discuss differing perspectives without rancor, and build on shared goals.

“Effective persuasion is about permanent changes in peoples’ minds, and the only way in which this can happen is by a two-way process of communication.”

Steve Denning