

Introduction

In July 2010, the Provincial Health Ethics Network (PHEN) was asked to provide feedback on *A Foundation for Alberta's Health System: Report of the Minister's Advisory Committee on Health*. Specifically, PHEN was asked to consider the report's four recommendations, accepted by Government and to be introduced in the Alberta Health Act in the Fall 2010 session:

1. Articulate a set of principles that must be sustained and maintained throughout Alberta's health system
2. Legislate an Alberta Health Act for the future, including the principles, provision for an Alberta patient charter, and other key elements to be developed in consultation with Albertans
3. Ensure ongoing citizen engagement in the development of legislation, regulation and policy
4. Develop clear directions to guide legislative, regulatory, policy and program delivery changes across the health system.

PHEN solicited feedback on the Report from several members of the bioethics community familiar with policy development. The purpose of this review was:

1. To consider the ethical issues reflected in the Report, specifically within the four recommendations
2. To envision, from an ethics perspective and in relation to this Report, the ideal health system for Albertans
3. In light of this consideration and envisioning, to consider how the four recommendations could best be practically realized to support an ethical organizational climate within the Alberta health system.

This document provides an edited summary of this feedback; it is not intended to be a position paper and does not express the organizational opinion of PHEN, which does not take stances as an organization.

Overall, participants felt that *A Foundation for Alberta's Health System* has the potential to positively shape and transform the organizational culture of Alberta's health system. However, its success in doing so will depend on the capacity to translate this guidance into practice, which obviously is extremely difficult, and to which due attention will need to be given.

Specific comments and feedback on each section of the document are provided below.

Recommendation 1: Articulate a set of principles that must be sustained and maintained throughout Alberta's health system

The principles outlined in this section are very broad, descriptive and inclusive, which is helpful for the reader to understand their purpose and importance.

In moral discourse, the terms *principle* and *value* are often used to refer to goods that are important in and of themselves and that cannot be further reduced to other goods. By this usage, *principles* and *values* are irreducible to other important ends. So for instance, one could argue that *fairness* is one of the principles that should underlie the health system – not just because societies with less inequity tend to be healthier, but because fairness in society could be considered valuable in and of itself, regardless of its other consequences.

If we apply this more refined usage of the terms principle and value to the document, an argument could be made for changing the term *principles* in the document to *goals* or *commitments* and, if appropriate, list within each what specific principles or values will guide the work of achieving them. This is because some of the principles identified in the document could likely be reduced to other important ends, and by this definition may not actually be fundamental principles.

Further, it may be beneficial to define and consistently use the terms *values*, *qualities*, *principles*, *goals* or *commitments* so it is clear to the reader what is meant by each term. For example, on page 10, the statement “The principles should exemplify the qualities of compassion, trustworthiness, equity, transparency and accountability” may be confusing, as what are called *qualities* here as often called *principles* in moral discourse as well as everyday use.

The statement on page 10 that the principles “be sustained and maintained” may be practically unattainable and may conflict with the statement that recognizes that “there is no hierarchy of importance” among the principles, and that they must be “balanced as decisions and choices are made across the health sector” (p. 17). That is, given the nature of ethical decision-making and principles themselves, they must constantly be balanced with each other and will necessarily conflict from time to time. For example, a “first available bed policy” may align with the commitment to *equitable access to timely and appropriate care*, but conflict with the commitment to *patient- and family-centered care*.

Those accessing and working in the health care system have a plurality of personal values that are always being balanced with these organizational principles. The ethical challenge is to try to reconcile or balance conflicting personal values and organizational principles in different situations and environments. This takes practice, education and judgment and requires a shift in organizational culture; thus, patients, families, care providers and administrators will require ongoing support in this area if the principles are to be committed to. Thus, serious consideration should be given to a well-supported and resourced process for translating the principles and guidance in this document into an organizational culture. Without this, the Act may well adorn shelves with great intention but without achieving any meaningful impact or change.

The suggestion on page 10 that a principle of sustainability be added seems reasonable and justified. In order to realize a responsible and sustainable health care system for Albertans, both sustainable resource allocation and environmental impact must be considered. Sustainability is mentioned on pages 10 and 13 and emphasized as important in the statement that the Minister's Advisory Committee on Health aims for a new understanding that will "sustain a public health system that is responsive, innovative and relied upon by this generation – as well as those to follow" (p. 34). Given the importance of such a value, we may do well to highlight it as a principle here.

An additional suggestion for this section is to add a principle (or *goal* or *commitment*, depending on the term chosen) that speaks to the importance of *fostering an organizational culture that understands the system's processes and continually seeks their improvement and strives for excellence*. This commitment to on-going quality improvement may be worthwhile articulating as a fundamental goal/commitment, equivalent in importance to the others.

Put people and their families at the centre of their health care

The commitment to put people and families at the centre of their health care is a welcome and important one. Consideration should be given however to one potential concern in doing so. In many cases, both the patient and the patient's family cannot be at the centre of care at the same time, because they are in conflict or because a decision based on what is best for the patient/client would be different than one based on what is best for the patient and family. For instance, in some circumstances, patients and their families disagree about treatment decisions, or family members disagree with each other, the health care team or substitute decision-maker. If the existing terminology of people and their families is kept, it may be worthwhile to explicitly recognize or address, either in the Act or elsewhere, the inherent tensions that may arise in moving towards a health system that more explicitly and concertedly maintains patients, residents, clients and their families at the centre of health care delivery.

Be committed to quality and safety

While use of the word "quality" here may be consistent with its usage in some health care literature, consideration could be given to changing it to the phrase "good quality" or "high quality", which are more accurate descriptions of the intended meaning.

The descriptive text in this section is quite self-referential, referring to many other principles mentioned elsewhere, including trust, respect, evidence-based decision-making, and people and family centered care.

Ensure equitable access to timely and appropriate care

The commitment to fairness articulated here is important and justified. Health care decision-makers are obliged to plan how care is going to be delivered and health resources allocated given limited resources, and a commitment to fairness when making these allocation decisions is central. The upshot of this is that difficult decisions are being made, and will have to be made, about hospital admission policies, where to make cuts when there is a budget shortfall, what services are to be insured, the construction and administration of

waitlists, rationing, discharge planning, and so on. As is quite evident, due to varying interpretations of fairness and justice, disputes often arise over what is fair and just in healthcare, making resource allocation decisions difficult, value-laden, ethical deliberations. For this reason, senior executive teams and others making these hard choices will need to be provided with the resources and expert advice required to support them in making informed, thoughtful and reasoned decisions, if this Act is to have meaningful impact.

Enable decision-making using the best available evidence

The Committee may wish to consider defining “evidence”, in particular to include qualitative research, not just quantitative research or ‘gold standard’ clinical trials.

Another point to consider here is that almost all health care decision-making is based on both some level of evidence, as well as often-implicit values and preferences. While greater attention to evidence-based decision-making in health care is common, what often remains unacknowledged or unaddressed is the role that values and preferences necessarily play in healthcare decision-making.

A simple example at the clinical level would be a decision to undertake, or not undertake, dialysis in end-stage renal disease. Such a decision would no doubt be based on the information and evidence available and presented. However, an individual’s values (e.g. how heavily one weighs quality and quantity of life, the weight one attaches to discomfort or inconvenience, one’s life plans, etc.) often do, and ought to, enter into such a decision. The danger of not articulating the importance of values-based decision-making and providing support for careful deliberation over such values, or of articulating only the importance of evidence at the exclusion of values, is significant. At best, a health system that insufficiently acknowledges, allows for, and supports good values-based decision-making can become driven by implicit or unstated value decisions without proper thought. At its worst and most extreme, it becomes railroaded by technology and what health care *can do*, at the expense of proper reflection about what it *ought to do*.

This tension manifests itself at the organizational and planning level in health care as well. The decision, for instance, to use health resources to expand a cardiology centre versus establishing a centre for pre-natal care for at-risk aboriginal mothers, will necessarily be based on some assumptions about what is most important, and about what fairness requires. These are extremely difficult issues, and, it could be argued, our society often makes short shrift of the need to identify the underlying values behind our decisions and evaluate them from the perspective of what is most important.

In short, some mention of the importance and critical nature of values-based decision-making may be well-placed here, and would counteract the tendency to focus exclusively on evidence-based decision-making.

Be focused on wellness and public health

The emphasis in this Report on wellness, public health and the social determinants of health is well articulated and justified. However, with the recognition of the social determinants of

health comes the necessity to place more emphasis and responsibility for health on other forms of association such as schools, workplaces, religious groups, community groups and neighbourhoods, which are not mentioned in the Report. Furthermore, focusing on wellness and public health necessitates providing health care professionals with the education and support to be responsive to the social determinants of health and work collaboratively with other jurisdictions to address them. Finally, citizens should be provided with the tools and interdisciplinary support to address the determinants of health in their own lives. Of course, these are all suggestions regarding what will need to follow the Act, rather than what needs to be in the Act, but they may be equally important.

Foster a culture of trust and respect

It is excellent to see the inclusion of this principle and the importance attached to it as a principle. It may be valuable here to include more emphasis on the importance of the human relationships between patients and health care providers and what they should look like in the ideal.

[Recommendation 2: Legislate an Alberta Health Act for the future, including the principles, provision for an Alberta patient charter, and other key elements to be developed in consultation with Albertans](#)

Patient Charter

The adoption of a Charter is also seen as a positive step towards ensuring that the health system is true to the principles outlined in the Alberta Health Act, and that patients have the right to a complaints process. Enshrining this commitment in a way that Albertans can refer and relate to and make their own makes it potentially a very valuable and powerful document.

One concern is that the Charter as it is presently outlined may place too much responsibility on the individual and not enough on society or the health care system, especially given the commitment in this Report to the social determinants of health. While it is important for individuals to assert responsibility for their health choices, it is essential to recognize that there are some individuals that are unable due to genetic or environmental causes or for whom it is unusually difficult to do so, and that a multitude of societal factors influence an individual's health – not just individual decisions. Thus, a statement regarding the responsibilities of the health system to help patients realize these responsibilities, where possible, may be warranted.

It may also be worthwhile to consider the addition of the responsibility of the patient to consider the effects of his or her decisions and conduct on the well-being of others, which would highlight the importance of healthy patient/provider relationships.

Arm's-Length Entity

The new arm's length entity will be an important body to provide research and help to inform decisions and set priorities with respect to drugs, devices, technologies etc. It is also

important to recognize that this or another body will need to provide expertise to address what values underlie these difficult resource allocation and priority-setting decisions. Furthermore, it will be essential to access expertise in engaging the public in this process of resource allocation, priority setting and other value-laden decisions.

Recommendation 3: Ensure ongoing citizen engagement in the development of legislation, regulation and policy

Engaging citizens in legislation and policy development is indeed central, and its inclusion in a document of this nature is an excellent step forward.

It would be valuable to consider how to develop and ensure the implementation of a transparent process of detailed information sharing about important health issues and the state of the health care system, including a formal consultation process that meaningfully engages citizens to consider the value-laden issues at hand in such a way that makes a difference to the process of policy development.

One of the common traditional flaws of engaging the public through citizen forums and online polls is that the people most affected by the issues discussed are not able to contribute to the process due to limited time, resources or access. Thus, special attention may need to be given to trying to reach these people, perhaps by specifically engaging individuals with identifiable expertise or experience in a particular topic or from a particular community. Relevant groups with access to these individuals, such as community and advocacy associations and organizations can also be utilized to assist in the consultation process.

Recommendation 4: Develop clear directions to guide legislative, regulatory, policy and program delivery changes across the health system.

The question of how the proposed legislation will be implemented and evaluated within the busy and ever-changing health system in Alberta is a difficult one that will need to be carefully addressed. Given that resources are limited, it is clear that it will not be possible to satisfy all of the aims of the Act at once. Compromises may thus have to be made, and this gives rise to the question of by whom these difficult, value-laden decisions would be made. The proposed legislation will require substantial, foundational and collaborative organizational changes and, as such, a commitment to careful, considerate and collaborative improvement at all levels of the system should be clearly asserted in the legislation.

Additional Comments

Recruitment

The report rightly asserts the need to recruit a health care workforce that will be adequate to the growing needs of Albertans. Consideration may need to be given, in order to be true to the principles of fairness and equity, to ensure an international recruitment process that is

responsible, equitable and sustainable for all those impacted (including not only Albertans) and consistent with the deep meaning of the principles outlined in the Report.

PHEN thanks the Minister's Advisory Committee on Health for the opportunity to review the report, *A Foundation for Alberta's Health System*, for considering this feedback, and for its commitment to meaningful consultation in the policy development process.

The PHEN office would be happy to provide any further clarification or support as needed for the further refinement of this important document.

*Provincial Health Ethics Network
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