



Review of Proposed Standards for Comprehensive Health Services

Submitted March 2000

Introduction

The Provincial Health Ethics Network (PHEN), in conjunction with the Canadian Council for Health Services Accreditation (CCHSA) and five Alberta Regional Health Authorities (RHA), held discussion sessions in January 2000 to review new draft accreditation standards arising from the AIM (Achieving Improved Measurement) Project.

The purpose of the sessions was to provide members of PHEN as well as representative staff and physicians from the RHAs, an opportunity (1) to reflect on the most important ethical issues that arise in the planning and delivery of health care and the promotion of health, as well as to envision what the ideal 'ethical healthcare organization' would look like if it were to appropriately address these, and (2) to consider the proposed new standards and provide feedback to the CCHSA to inform future drafts of the document in light of this reflection.

The discussion sessions were held in Grande Prairie, Ft. McMurray, Calgary, Edmonton and Lethbridge, Alberta. A combined total of 105 individuals attended the sessions, representing a cross-section of stakeholders in the health system from patients and front-line staff to administrators and board members. Discussions were held in plenary format, as well as in small group sessions where numbers warranted.

The following provides a summary of the comments and concerns arising from these discussions. This document is not intended to be a position paper and does not express the institutional opinion of PHEN or any of its RHA partners.

For the purposes of the discussion sessions and this document, the term 'ethical issues' has been assumed to refer to questions that, at their core, involve potentially competing values. Since most decisions involve and are based on (often implicit) value assumptions, the scope of issues which have ethical implications in the health setting, by this definition, is vast. In this broad sense, all sections of the accreditation standards have ethical implications. In order to undertake a more manageable task, the sections of the standards that were reviewed, analyzed and discussed were those which were seen to have the most serious or pressing ethical implications for health care providers, administrators, policymakers and those whom they serve.

This summary is divided into two sections. Section 1 provides an overview of comments made of a general nature regarding the draft Standards and attempts to

reflect the general tenor of the discussions. Section 2 provides detailed suggestions or questions that arose from closer examination of the Standards for each sector. While every effort has been made to accurately reflect the most salient concerns and suggestions raised, the statements below do not necessarily represent a consensus, particularly as participants in different cities did not have the benefit of reflecting on each other's comments. Those concerns which were almost unanimously expressed in the sessions are specially delineated below with an asterisk to suggest that the CCHSA may wish to pay closer attention to these areas, given that participants seem to have considered them particularly problematic.

Section 1: General Comments

Participants were clearly supportive of, and positive regarding, the incorporation of ethical considerations throughout the Standards. It was felt that the pervasiveness of ethical issues in the actual delivery and planning of health systems was well recognized in the documents as evidenced by the manner in which various parts of the Standards have been imbued with references to the need for ethical reflection and action. The CCHSA was congratulated for its willingness to solicit and receive feedback regarding the draft documents, and in particular in regards to the consideration of the Standards from the perspective of ethics issues.

Many attendees expressed a general sense that while the more comprehensive inclusion of ethical considerations in the Standards was a positive step, its wording in certain sections was vague and potentially left too much room for interpretation in individual circumstance. The fear was expressed that any ambiguity in regards to the need to address ethical issues may have the unintended effect of 'watering down' these potential strengths of the new Standards. For instance, the requirement to have in place processes to help staff and clients deal with ethical issues was seen by participants to be at least as important as other, traditionally more widely recognized, service obligations of healthcare organizations such as the need to ensure competency of staff or the availability of a comprehensive set of diagnostic and treatment services. Yet in reality, the former is rarely treated with the same seriousness, or receives the same level of institutional support (proportionate to need) as the latter. The result is frequent relegation of the obligation to address ethical issues to 'optional' status within healthcare organizations, to be supported when resources allow (which they rarely do) and after the 'real work' in healthcare organizations has been done. Because of its status as an optional element in health planning and delivery, many participants suggested that that the CCHSA consider, wherever possible, tightening the wording regarding requirements for addressing ethical issues, thereby underscoring the fact that ethical planning and delivery of services is a necessary rather than elective component of providing quality care.

Finally, participants expressed a general unease with the way in which ethical issues are often addressed in theory as opposed to practice in the health setting. While health organizations occasionally have in place policies and procedures for dealing with ethical issues (such as for incorporating ethical considerations into resource allocation decisions and for soliciting input regarding the values of the community and staff when setting strategic direction), participants were generally cynical about the translation of such commitments into practice. Attendees suggested that the CCHSA place as much emphasis as possible, *during the process of accreditation* and possibly in the Standards themselves, on the demonstrated commitment of health organizations to ‘living’ and ‘bringing to life’ their stated values and ideals.

Section 2: Detailed Suggestions/Questions

Leadership & Partnerships

(A) 2.0 *The organization delivers services and makes decisions in accordance with recognized codes of ethics or the organization’s own ethical guidelines.*

Concern was expressed regarding use of the word ‘or’. As is, the statement suggested to participants that health organizations were free to develop their own set of ethical guidelines in the event that they chose not to abide by the recognized codes of ethics of, for instance, those of certain professional associations. While this was likely not the intent behind the statement, a change in syntax, structure or content may remedy the potential confusion. Suggestions included changing ‘or’ to ‘in addition to’, or modifying the sentence to read something similar to “The organization delivers services and makes decisions in accordance with a defined code of ethics or set of ethical guidelines”.

(B) 2.1 *The governing body develops, regularly reviews and updates organizational policies on ethics issues.*

- This was seen to be a positive and important component of the Standards. It was suggested however that the governing body should be *responsible for* ensuring that these obligations are carried out, and may not wish to develop and review policies itself.
- Some comments were made that having in place a process to address ethical issues was far more important than having policies to address them. It was suggested that policies are often established and then flounder in obscurity, and that no set of policies could address the large scope of ethical issues that arise in the health setting. There may be some place however, for policies which address the most common, pressing

ethical issues which present themselves in health organizations. These might include the withdrawal/withholding of care, use of do not resuscitate orders, recognition of advance directives, and obtaining informed consent. With this in mind, the clause could be amended to read something similar to “The governing body develops, reviews and updates organizational policies on the most commonly faced ethical issues”.

- An interesting distinction was made during the discussions between developing policy to address ethics issues and developing ethical policy to address issues. Article 2.1 of the Standards addresses the former but not the latter. Deceptively, many policies may not, on first glance, appear to have ethical implications. To address this possible omission, article 2.0 could be amended to read “The organization delivers services, makes decisions and develops policy in accordance with a defined code of ethics or set of ethical guidelines”. This places the emphasis on incorporating ethical considerations into the making of policies, rather than the relatively more common practice of reviewing them for ethical implications after they are developed.

(C) * 2.2 *The organization has processes for dealing with ethics issues and concerns.*

- Again, this was thought to be an important and almost universally poorly addressed obligation of health organizations. It was suggested that the word “recognized” be added before “processes”. The lack of general awareness within health organizations of existing processes to deal with ethical issues was a serious concern. Participants felt that a majority of staff within health institutions were not cognizant of the existence of ethics committees to assist them in decision-making. Thus, any means of ensuring that health organizations take serious efforts to ensure such processes are more widely recognized and accessible, was thought to be valuable.
- Participants also felt it important to indicate that the nature of ethics issues to be addressed includes both clinical (e.g. withdrawal of care, refusal of care) and administrative/organizational (e.g. conflict of interest, resource allocation).
- The third concern raised regarding this clause, and one that stirred significant discussion at the sessions, was that it may not be sufficiently prescriptive. Participants discussed extensively the issue of whether health organizations should explicitly be required to have ethics committees, or, at a minimum, access to formal ethics bodies to help staff and clients deal with ethical issues. The reasoning behind this suggestion was the fear that many organizations do not take seriously the requirement for having processes in place to address ethics issues, and may attempt to fulfill it by

pointing to the use of such informal methods as ‘hallway’ consults with respected care providers, or discussions with colleagues. While such informal methods of addressing ethical issues were seen to be warranted or beneficial in some circumstances, many participants were concerned that they might substitute for a formally established body such as an ethics committee composed of individuals with carefully chosen expertise or aptitude. Just as psychiatric consults would not be appropriately handled by a surgeon, some suggested that ethics consults should not be assumed to be adequately addressed by individuals without background or training in ethical decision-making. This was not to suggest that qualified members of ethics committees or formal ethics bodies had unique access to ‘moral truths’, but rather that these members often had the experience and ability to dissect complex ethical issues and suggest ways of approaching them in a systematic and reasoned manner. On this basis, it was suggested that the CCHSA may wish to give some thought to altering this clause to require that a *formal* process be in place for addressing ethical issues faced by clinicians, administrative staff and clients.

- A related issue to the question of formal versus informal processes for addressing ethical issues involves the nature and quality of that process. While the draft Standards presently require only that a process be in place, several participants suggested that there is a need for quality control in this area. However, modifying the Standards to require a *quality* or *effective* process for dealing with ethical issues would not, it was agreed, address this concern, since the level of quality or effectiveness would then be a subjective judgement which the accreditor may not be in an appropriate position to make. It was not clear from the discussions how this difficulty could be resolved¹.

¹ Facilitator’s Note: The CCHSA may wish to refer to two potentially helpful documents in addressing this concern:

- (A) The **1998 Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans**, outlines the membership requirements of an ethics review board to approve research conducted on humans in Canada. The CCHSA may choose to take the route adopted by the Tri-Council group and indicate the minimal essential requirements of an ethics review process in the clinical setting, much as the above document does for the research setting. See <http://www.nserc.ca/programs/ethics/english/sec01.htm#A>.
- (B) Alternately, the CCHSA may wish to adopt the approach of the JCAHO by outlining in supporting documentation to the Standards the various ways in which health organizations may address implementing a process to deal with ethics issues. These could include:
 - having access to the ethics services of another health organization or institution
 - patients and their families are informed of how to gain access to the ethics committee and the process for ethics issues resolution
 - a health organization has access to a 24-hour consulting service to help resolve ethical issues

(These three examples are taken from the **Joint Commission on Accreditation of Healthcare Organizations Comprehensive Accreditation Manual for Hospitals: The Official Handbook**, Standard RI.1, Example of Implementation for RI.1)

- A final issue to which this clause gives rise is the adequate resourcing of processes to address ethical issues. Attendees were clearly concerned that while health organizations may put in place such processes, these may not be adequately supported by the organizations which they are created to serve. In particular, the support of these processes – both financial and ‘moral’ - by the organization’s administration and its governing body, was thought to be crucial to their success and efficacy. Some participants felt that it may be valuable to addend a clause to this criteria stating that “Processes to address ethical issues within healthcare organizations receive adequate financial and administrative support from the organization to function effectively”.

*(D) * 2.3 Staff, service providers, volunteers and students receive ongoing education to help them understand and resolve ethics issues.*

It was suggested that board members or members of the governing body be included in this list because of nature of the decisions they are required to make. Several participants also suggested that physicians be included in this list, on the assumption that physicians are not considered to be staff in many health organizations.

*(E) * 8.0 Human, financial and physical resources are appropriately allocated throughout the organization*

8.1 The governing body and managers appropriately allocate resources by: ...

8.2 When making decisions about how to allocate resources, the governing body and managers

- *consider ethics, values, social costs and benefits...*
- *fairly distribute resources across population groups, geographic regions, and the continuum of service*

Article 8.0 of the Leadership and Partnerships Standards gave rise to substantial concerns at all of the five discussion sessions.

- Most participants felt that the section was too vague, and that while its intentions were laudable, inclusion of references to consideration of values and ethics, including fairness, was insufficiently clear or strong to be meaningful.
- Participants were particularly concerned with the phrases ‘appropriately allocate resources’ and ‘fairly distribute resources’. These phrases were recognized as being heavily value-laden in the particular context in which they appear here. As a result, any assessment by an accreditor based on criteria that included those terms would by definition require the

accreditor to make significant value-based decisions about whether the distribution of resources within a given health organization was in fact fair or appropriate. Yet the question of whether resources have been allocated fairly in a health system is vast and incredibly complex. It would be inappropriate, participants felt, to leave such a determination to the accreditation team.

- Suggestions for amendment, either individually adopted or used in concert, included:
 - 1) Changing 8.0 to read “Processes are in place for appropriately allocating human, financial and physical resources throughout the organization”. This shifts the subject of valuation to the process rather than the allocation of resources themselves.
 - 2) Removing the word ‘appropriate’ from 8.1. This shifts the emphasis to the need to incorporate the practices listed in the sub-bullets, without intimating that conformity with each of those practices would result in the appropriate allocation of resources.
 - 3) Altering 8.2 to deal exclusively with ethics and values, and in particular to require that “The governing body and managers have in place a process for allocating resources that takes into consideration ethics and values by:
 - i. Basing decisions regarding the allocation of resources on the considered values of the organization or a predetermined values/ethics framework
 - ii. Explicitly considering issues of fairness/equity in the distribution of resources across population groups, geographic regions & health sectors
 - iii. Making the resource allocation process and criteria explicit and transparent
- Several participants felt that the third bullet under 8.2 was not a reasonable expectation on the basis that resources could seldom be ‘easily’ moved to where they are needed most. This clause, participants feared, was redolent of a governing board that transferred resources from one locale to another with ease from the standpoint of those not impacted by such a reallocation and without due consideration of its deleterious effects on staff and health care beneficiaries.
- Several session attendees noted that often, the resources which governing board and managers are given to work with are insufficient to deliver appropriate levels and quality of care. Several participants thus suggested that the responsibilities of governing board members included advocating for appropriate levels of resources in such situations, and that such a

requirement could be laid out somewhere in the Leadership and Partnership Standards.

- The suggestion was made that the Leadership & Partnership Standards make reference to the leadership's responsibility for fostering an environment of trust and open communication. The creation of such an enabling environment, it was argued, would do far more to avert crises, disagreements and potential ethical conflicts, than would the development of institutional policies on divisive moral issues.

(F) *17.0 The organization conducts or participates in appropriate research activities.*

- A common concern with this section of the standards was that there did not appear to be a requirement to make clear what a health organization defined to be research. This was based on the observation that health organizations sometimes collect data under the name of quality assurance, quality improvement, or other informal techniques that might more accurately be defined as formal research requiring ethics review. It may be beneficial to include a section (perhaps 17.1, bumping the other sections up in number) which states that the organization have a clear definition of what is considered to be research. If such a clause is included, the use of the descriptor "formal" before "research" could be dropped from 17.2.

(G) *17.1 An external reviewer or review body reviews all formal research projects the organization participates in. The review includes...*

- Participants suggested clarification regarding the term 'external reviewer or review body'. Questions raised included: (1) whether 'external' referred to both the reviewer and the review body (2) whether this referred to a process that was external to the researcher, or external to the organization? If the latter, it was felt that very few health organizations would be able to meet this criteria. An alternative may be to refer to a process that is "at arms length from the researcher" or a similar wording².
- The suggestion was made that a bullet be added to 17.1 to look at "other ethical implications", since the ethical implications of research are not exhausted by reviewing the benefits and risks to participants and the process for obtaining informed consent
- It was noted that the "process for obtaining informed consent" could be clarified by adding "including for the use of both identifiable and non-identifiable health information", as research subjects are often unaware that their 'non-identifiable' health information is being submitted to

² See Article 1.2 of the 1998 Tri-Council Policy Statement: *Ethical Conduct for Research Involving Humans*.

provincial or national bodies or used for informal aggregate data/research studies.

Care Delivery Sectors

The comments below apply to the Standards for several or all care delivery sectors, unless indicated by reference to one specific set of Standards. For simplicity, the section numbers cited below for those comments that apply to several or all sets of Standards will be those used in the *Acute Care Services* document.

(A) 7.1 There is a process for determining whether clients are capable of making informed choices...

It was suggested that the third bullet under this section be expanded to include the provision that a process be in place for determining who will be the substitute decision-maker in situations where the client cannot make informed decisions.

(B) 7.2 The team obtains the clients' consent to provide services by using a process that includes...

- *explaining the options for service, the expected benefits and risks, the risks of refusing service, and the resources available*
- *presenting information so that the clients understand*
- *giving the information verbally and in writing...*

- In regards to the first bullet, some attendees commented that the risks of accepting service were as important to know as those of refusing service. Therefore, the clause could be amended to read “explaining the options for service, including the expected benefits and risks of accepting and refusing service, and the resources available...”

- Due to the problematic nature of obtaining informed consent from those who are not able to communicate in the language of the care provider, it was suggested that the second bullet be amended to read “presenting information so that the clients understand, making use of reliable and competent translation services where necessary”

- Several participants suggested that it is often not reasonable to provide information in writing, particularly in the long term care setting. Adding “if appropriate” before “in writing” may obviate the difficulty.

- In keeping with the need to respect and be sensitive to cultural differences, especially in situations of working with clients whose cultures adopt a different approach to informed consent from the predominant western ideal (such as one of ‘weak paternalism’), it was recommended that an

additional clause be added to suggest “being respectful of cultural differences and attitudes towards individual decision-making and consent”.

(C) (Long Term Care) 7.2 The team actively involves clients in making decisions about their lives and encourages them to make personal, day to day choices about ...

Several respondents noted that the list of bullets following this clause was not exhaustive of the types of choices that clients can ideally make. It may thus be appropriate to add the phrase “such things as:” after the word “about”.

(D) 7.5 When clients are mandated to receive services or where choice is limited due to legal requirements

It was suggested that a third bullet be added to this section indicating that clients or substitute decision-makers’ options for appeal are made clear to them under these circumstances.

(E) 10.5 The team verifies that the clients and families understand the information given

This requirement, it was suggested, could be elaborated upon. Bullets could be added to suggest how a team may go about verifying that clients and families understand information given.

(F) 11.3 There is a process to help staff deal with ethical issues...

Several participants suggested changing the clause to read “There is a process to provide education and support to staff in dealing with ethical issues”. This clarifies what is meant by ‘helping’ and underscores the importance of education in addressing these issues.

(G)(Acute Care) 11.4 The organization has a process for procuring and donating organs and tissues that includes...

- *using set criteria to identify potential donors*
- It was pointed out that the syntax of the clause may not be correct, since organizations themselves do not donate organs. Placing ‘the’ before ‘procuring’ may resolve this problem.
- Suggestions were made to include the word ‘effective’ before ‘process’. Concern was raised that many organizations have processes for procuring organs, but a significant number of these are relatively ineffective.

- It was proposed that the first bullet of 11.4 be modified to read “Potential donors are identified through a process that involves considerations of fairness and equity”.

(H) 11.6 The clients’ privacy and confidentiality is protected by...

- *...obtaining the clients consent to share personal information with their families and other organizations...*

It was proposed that the scope of this clause be expanded to address concerns about the growing demand for health information from private sources - particularly insurance companies - and the frequency with which clients provide ‘official’ consent without thoroughly understanding the implications of doing so. An amended bullet could refer to “obtaining the clients consent to share personal information with their families and other organizations such as insurance companies, and ensuring that clients appreciate the implications of releasing this information”.

(I) 14.13 The organization uses seclusion or restraints to control or modify problem behaviour only when all positive methods have failed...

While this section makes reference in the third bullet to the need to consider ethical issues in the decision to use restraints, some participants suggested amending the first bullet to suggest that the “set criteria” be arrived at through consideration of ethics issues. In particular, the desire to protect the client and others against harm needs to be balanced against the obligation to promote client self-determination and autonomy.

(J) A final concern that was raised did not necessarily refer to one particular section of the Standards. Some participants questioned whether ethical issues arising from a regionalized health system are or could be adequately covered by Standards that are divided into sectors. Such issues might include:

- The transfer of patients from long term care facilities to acute care. Questions that arise in such situations include whether or how, for instance, a do not resuscitate order would follow a particular resident/patient, and whether it would remain in effect in transit.
- The establishment of local versus regional processes for addressing ethical issues. Should a process to address ethics issues or an ethics committee serve an entire region, or only one or two institutions within it? How would consistency in ethics standards be maintained if institutions within a regional health system developed their own guidelines?
- The relations between regional health systems and contractors in regard to ethics issues. If the requirement of having processes to address ethical

issues extends to contractors of a regional health body, what processes can be established to ensure that the requirement is met? If the contractor is a Catholic or other religion-affiliated facility, with its own distinct values and guidelines, in the event of a conflict over a difficult moral issue, whose values and which processes ought to guide the final decision – those of the secular regional health body/funder, or those of the organization delivering the services?

While the above comments reflect detailed analysis of the various components of the draft Standards, participants reiterated at the conclusion of the sessions that they were pleased with the progression and the development of the new standards, and with the recognition of the importance of incorporating ethical considerations into all aspects of the health system.

The Provincial Health Ethics Network would like to thank all those who attended the discussion sessions, its RHA partners and organizing staff, as well as the Canadian Council on Health Services Accreditation for their interest in and support for this project.