Health Care Decisions and End-of-Life Issues: Terms of Reference for a Possible Project

A Report prepared for the British Columbia Law Institute by
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(a) promote the clarification and simplification of the law and its adaptation to modern social needs,

(b) promote improvement of the administration of justice and respect for the rule of law, and

(c) promote and carry out scholarly legal research.

The Institute is the effective successor to the Law Reform Commission of British Columbia which ceased operations in 1997.

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Introductory Note

Early last year the British Columbia Law Institute entered into an arrangement with the Public Guardian and Trustee (PGT) for the development of terms of reference for a possible study on healthcare decisions and end-of-life issues. The particulars of the arrangement and its initial scope were set out in a letter dated January 31, 2001 from the PGT to the Institute:

This letter is to confirm that the Public Guardian and Trustee of British Columbia will contribute to the BC Law Institute for the development of Terms of Reference for a study that will address but not be limited to the following:

Explore health law issues related to the *Health Care (Consent) and Care Facility (Admission) Act* with particular attention to substitute health care decision making as it applies to end of life issues;

Identify legal and ethical dilemmas within the substitute decision making provisions of the Act;

Consider the concept of the "patient's best interests" in the context of the comatose patient;

Consider the appropriate division of decision making between health care providers and other decision makers in the context of proposals to treat and proposals to withhold or withdraw treatment;

Consider the role, jurisdiction and functioning of mechanisms to resolve disputes;

Consider the extent and nature of consultation to be undertaken for purposes of the study and the process that should be adopted;

With the implementation of the Adult Guardianship Legislation, and in particular the *Health Care (Consent) and Care Facility (Admission) Act*, issues have arisen where there is not a common understanding of the provisions in the legislation, and which are not easily resolved with the development of policies and procedures.

The purpose of this project is to develop Terms of Reference to identify the issues and describe a process for discussion and clarification. During the development of the Terms of Reference, we look forward to discussions that would include an informational meeting with the members of the Health Care (Consent) and Care Facility (Admission) Planning Group of the Public Guardian and Trustee.

To assist in carrying out this task the Institute engaged Professor Stephan Salzberg of the Faculty of Law, University of British Columbia who consulted with officials of the PGT and others concerned with the administration of the relevant legislation. In June 2001, Professor Salzberg presented to the Institute's Board of Directors a Report setting out the proposed terms of reference he had developed. The Board met twice to discuss the Report which it endorsed and submitted it without change to the PGT.

Following its submission in July 2001 the Report was considered internally within the office of the Public Guardian and Trustee and the Ministry of Health Services. The latter Ministry is in the process of developing a strategy to address a variety of health care issues through a number of initiatives. This includes development of a provincial strategy for end of life care under the auspices of the Minister of State for Intermediate, Long Term and Home Care.

As a result of this development, the Law Institute does not expect to play any further role in relation to this topic although it is our understanding that Professor Salzberg's Report will assist in informing these processes and constitute an important contribution to the ongoing debate.

Readers may also wish to note a more recent development in this area. In March 2002 a Report was submitted to the Attorney General by Professor Emeritus Albert J. McClean, Q.C. setting out recommendations designed to clarify the respective roles of representation agreements created under the *Representation Agreement Act* and enduring powers of attorney created under the *Power of Attorney Act*. This Report may be found on the Internet at:

http://www.ag.gov.bc.ca/public/McClean-Report.pdf

Over the past year, it has become clear to the Law Institute's Board that the work carried out by Professor Salzberg is of wider interest. Hence a decision was made to publish his Report as a formal Institute document.

Gregory K. Steele
Chair, British Columbia Law Institute
September, 2002

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A. Introduction

These proposed terms of reference have been developed pursuant to a request from the Public Guardian and Trustee of British Columbia (PGT) to consider a number of issues relevant to the *Health Care (Consent) and Care Facility (Admission) Act*.[1]

Those issues are linked to difficulties that have arisen with respect to the PGT's role as a surrogate decision maker for health care decisions under the HCCF Act. It is important to note, however, that the issues discussed herein extend to implementation of two other statutes that also came into force as of February 28, 2000, the *Representation Agreement Act* [2] and the *Adult Guardianship Act* [3] (which remains largely unproclaimed). Both of those acts make provision for surrogate health care decision makers, as does the *Patients Property Act* ,[4] first enacted in 1962, which is still used as a basis, pending proclamation of the *Adult Guardianship Act*, for surrogate health care decision making.

The concerns which have arisen, moreover, in the context of the PGT's role and actions under the HCCF Act are relevant not only to the PGT, but are also of great importance to all members of the general public who may serve as surrogate decision makers under any of the above noted statutes.

The issues that are to be addressed herein, under the terms of the PGT's request, which is set out as Appendix 1 to this document, are extremely wide-ranging and, to a large extent, open-ended. For purposes

of treatment in this document, however, they have been organized into the following six categories, consisting of issues related to:

1. The criteria and process by which adults are found to be incapable of making health care decisions,
2. The scope of temporary substitute decision makers' authority,
3. The criteria applied by surrogate decision makers[5] in making health care decisions, and their application in the context of end of life decision making,
4. The way in which decisions regarding general health care directives, such as "do not resuscitate orders" ("DNR orders") and "levels of care" instructions may or may not fit within the scheme of the Act,
5. Possible frameworks for decision making with respect to them, and
6. Mechanisms for the resolution of disputes under the Act, particularly the role and jurisdiction of the Health Care Review Board.

Each set of issues will be addressed in turn in succeeding sections of this document. The remainder of this introduction discusses briefly the principles that inform their framing of those issues, especially those in categories 1 through 5.

B. The Principle of Autonomy and Decision Making in Health Care

The Hippocratic tradition, which had been for centuries the dominant force in structuring the physician-patient relationship in mainstream Western medicine, is based on a paternalistic model in which the physician, a highly trained professional guided by the ethical principles of beneficence and non-maleficence, makes decisions that are in the best interests of the patient. The common law has, from very early times, circumscribed the prerogatives and power of physicians, at first through the vehicle of consent and the tort of battery: intentional, offensive touching for which consent has not been given. The requirement of consent represents recognition of a countervailing principle, that of patient autonomy in health care decision making. The principle of control over one's own bodily integrity through the mechanism of consent has received perhaps its most eloquent expression in the words of Justice Cardozo in *Schloendorff* v. *New York Hospital* ,[6] oft-quoted in Canadian jurisprudence: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."

This concept of consent as a protective mechanism has been extended in many common law jurisdictions, including Canada, to form the doctrine of informed consent. The underlying notion of informed consent involves a recognition that, for a person's decision making regarding health care and thus control over one's own body to be meaningful, that person must have the necessary information to make an informed choice whether to give, refuse or revoke consent. Thus the common law has imposed an obligation upon health care providers to provide information material to the person's choice. Failure to do so, should it cause injury to that person, will, in Canada, sound in negligence. The well known Supreme Court of Canada cases, *Hopp* v. *Lepp* [7] and *Reibl* v. *Hughes* ,[8] establish this principle in Canadian jurisprudence, founding it squarely on the principle of autonomy.

The spirit of patient autonomy informs the HCCF Act, which purports to codify common law principles and developments. Adults are presumed to be capable of giving, refusing or revoking consent to health care,[9] in the absence of a finding of incapability. An adult's way of communicating will not, by itself, be grounds for a finding of incapability.[10] Section 5 of the Act, setting out an adult's consent rights, places the adult at the very centre of health care decision making, not only as far as the giving, refusing or revoking of consent to

health care, but the right to select a particular form of available health care on any grounds,[11] and to be involved to the greatest degree possible in all case planning and decision making.[12] Subsections 6(e) and (f) codify the informational explanation and disclosure requirements of the doctrine of informed consent.[13]

The scheme put in place, under the HCCF Act, as well as the *Representation Agreement Act* and the as yet unproclaimed provisions of the Adult Guardianship Act, aims to ensure, both through the method of designating surrogate decision makers and the criteria to be applied in making surrogate decisions, that the adult's wishes are, insofar as possible, respected.

As particular issues are identified and articulated in the sections that follow, it is important to bear in mind that, in almost every instance, the principle of autonomy is implicated. Consideration of that principle and how it can be reinforced in the formulation and implementation of the Act has been, together with difficulties that have been encountered during the short period that the Act has been in force, a prime factor in selecting the issues presented in these proposed terms of reference from within the broad range of issues that fit within the scope of the mandate out of which these terms arose.

I. Determinations of Incapability

A. Issue Ia: Does the Act, as currently written, adequately embody and encourage best practice with respect to determinations of incapability?

Under the Act, adults are presumed capable of giving, refusing or revoking consent to health care, under section 3 of the Act, unless a health care provider (defined, in section 1, as "a person who, under a prescribed Act, is licensed, certified or registered to provide health care") determines, pursuant to section 7, that the adult does not understand the information which must be given in the course of obtaining informed consent, or that the information applies to the situation of the adult. If an adult is deemed incapable, there is not an emergency and there are no other legally authorized surrogate decision makers who are capable and available, the health care provider is to appoint a temporary substitute decision maker ("TSDM") from a hierarchical list of relatives set out in section 16.

The TSDM is authorized, under section 17(1), as a surrogate decision maker, to give or refuse substitute consent to health care[14] on behalf of the adult for a period of 21 days from the date of being chosen. Under section 16(3), should no one in the categories of relatives set out in section 16(1) with the qualifications set out in section 16(2) be available, the PGT, or someone chosen by them, serves as the TSDM.

Given that the Act values the adult's autonomy to the greatest degree, it is important that surrogate decision makers either not be appointed or called upon to make substitute decisions unless there has been a clear, reliable determination of incapability that is specific both to the time in question and to the particular treatment that is being proposed or considered. Capability (or incapability) is not a constant. Instead it may fluctuate, even from hour to hour. Moreover, one may be capable for certain decisions and not for others. Clinical practice may reflect an appreciation of the fluidity of capability, although one assumes that in practice it varies depending on the institution, the particular health care provider and the circumstances. The question is whether the Act adequately addresses and informs the ways in which incapability is determined.

A critical question to ask is whether the Act serves to ensure that incapability determinations will be carried out with sufficient frequency. Section 17(1) of the Act limits the time period within which a TSDM can exercise substitute decision making authority to 21 days from the time of being chosen. In order for a further appointment of a TSDM, there would have to be another determination of incapability. Thus the

section ensures that, at a minimum, there be at least one such determination every 21 days. As a matter of clinical practice, there may be more frequent determinations. It is not clear however that a minimum requirement of a determination every 21 days is sufficient to ensure that incapability determinations are conducted with sufficient frequency and at appropriate times to the protect the adult's autonomy.

The danger to be avoided is application of the label "incapable" for longer than is necessary and for situations where it may not be accurate. Section 5(2) provides that a health care provider should not seek a surrogate decision maker's decision to give or refuse consent "unless he or she has made every reasonable effort to obtain a decision from the adult." Does the latter phrase adequately convey to health care providers an obligation to make a full and separate determination of incapability before proceeding to a surrogate decision maker?

Another difficulty may present itself. There may be subtle differences in the approach that a health care provider takes in gauging incapability once an adult has been deemed incapable, posing dangers that legislation might also address. Even if best practice and/or legislation mandating or encouraging best practice were in place and complied with, in subsequent determinations of incapability the statutory presumption of capability under section 3 of the Act may be compromised. An evaluation of the adult may be framed, even unconsciously, in terms of seeking evidence to remove a label, and a concomitant presumption, of incapability.

These possible difficulties with the current Act raise the following issue:

> **B. Issue Ib: If the Act does not encourage or mandate best practice as to determinations of incapability, should the Act, through amendment of section 7, section 5 or other means, specify that a determination of incapability is to be made each time that a health care decision is required, and that the presumption of capability is to be respected in every such determination?**

The need to ensure that there is an ongoing and accurate determination of incapability is underlined when one considers, for instance, that the definition of "health care" in section 1 of the Act includes "a course of health care, for example, a series of immunizations or dialysis treatments or a course of chemotherapy." Consider a situation where a surrogate decision maker for an adult has consented to such a course of health care. Given that, under section 4, an adult has the right to revoke consent and to have the decision to revoke consent respected, it would seem imperative to clarify, in the Act, that the health care provider has an obligation to determine, prior to each discrete provision of health care in such a "course of health care" that the adult is incapable with respect to that particular decision at that particular time, is thus not able to exercise the right to revoke or refuse consent.

Given the Act's emphasis on protection of the autonomy of the adult and use of the substitute decision making scheme only as a last resort, it is suggested that consideration be given to appropriate amendments to the Act to ensure the fullest possible attainment of those goals.

Method:

1. Search of the medical and medical ethical literature regarding best practice as to relevant aspects of incapability determinations
2. Selective survey of practice with regard to incapacity determinations and substitute consent in a sample of representative British Columbia institutions, including those providing chronic care

and common "courses of health care," and
3.Review of case law and statutes in other jurisdictions.

II. Scope of Temporary Substitute Decision Makers' (TSDM's) Authority

Issue II: Is it necessary to harmonize references in the Act to TSDM authority with respect to substitute decision making surrounding health care in order to clarify that TSDMs have authority not only to give and refuse, but also to revoke consent to health care?

Certain sections of the Act refer to the TSDMs' authority to "give or refuse substitute consent," while others refer more fully to authority to "give, refuse or revoke substitute consent." Section 19 provides the most conspicuous example, even as between succeeding subsections. Sections 19(1), (1)(a) and (2), which set out the hierarchical criteria to be employed by a TSDM in making substitute decisions (discussed below), only refer to giving or refusing consent. Section 19(3), in discussing factors to be considered in deciding as to the adult's "best interests," a criterion referred to in section 19(2), speaks of giving, refusing or revoking consent on the basis of that same criterion.

There are inconsistencies as between other sections as well. Section 16(2) refers to giving, refusing or revoking substitute consent, while section 17(1) refers only to giving or refusing. Section 28, dealing with the Health Care and Care Facility Review Board's jurisdiction to review surrogate decisions makers' decisions (discussed below in Issue V) refers to giving, refusing or revoking.

Perhaps the most significant instance of inconsistent usage occurs in section 18, concerned with restrictions on the authority of a TSDM. In section 18(2), TSDMs are granted limited authority to "refuse substitute consent to health care necessary to preserve life." (The same wording is found in section 21 of the Adult Guardianship Act, an unproclaimed provision dealing with the authority of surrogate decision makers under that Act). Taken literally this would give authority to have such health care withheld, but not withdrawn. It is unlikely that such a meaning was intended. Moreover, it does not make sense to impose a forced interpretation, reading, for instance, the "refuse" of section 18 to include "revoke" as well (an extremely strained reading when both words appear in other sections).

It should be determined whether these inconsistent references are a merely a matter of drafting, to be harmonized through a simple amendment, or whether they in fact reflect differences in authority given to TSDMs under varying circumstances intended to be incorporated into the Act.

Method:

1. Consult with drafters of the Act
2. If it appears that this is merely a matter of inconsistent drafting, suggest technical corrections
3. otherwise, analyze the implications of the inconsistent references in light of the purposes and scheme of the Act.

III. Criteria for Substitute Decision Making With Regard to Health Care [15]

What criteria is a TSDM to apply in making decisions on behalf of the incapable adult? Section 19 of the HCCF Act sets out criteria reflecting a hierarchy that has received wide recognition in the bioethical literature. That hierarchy is usually expressed, as it is with some modification in the Act, as follows:

Adult's current wishes? wishes expressed while capable? known beliefs and values? best interests

This hierarchy is in keeping with the principle of autonomy. To the extent possible the surrogate decision maker is to attempt to effect the instructions or wishes that the now incapable adult made or would make. Insofar as those instructions or wishes were actually expressed by the adult or may be imputed from known beliefs and values, they may be said to represent the subjective wishes of the adult, reflecting the particular attributes, views and idiosyncrasies of the adult. A "best interests" determination, the determination of last resort, constitutes an "objective" judgment. Under the HCCF Act's scheme, that pure objectivity is modified somewhat by the requirement that the TSDM consider the adult's current wishes in making a best interests judgment, although the role that the adult's current wishes is to play in the hierarchical scheme is not entirely clear.[16]

The criteria set out in section 19 of the Act are of importance not only for TSDMs. All surrogate decision makers under the *Representation Agreement Act* (i.e. representatives, those granted authority to make health care decisions in a representation agreement made by the adult while capable) and unproclaimed portions of *Adult Guardianship Act* (court-appointed substitute decision makers and guardians) are to apply similar criteria.[17] Clarification of the criteria and the way that surrogate decision makers are to apply them is of great importance with regard to all health care decisions. Their importance may be magnified when the surrogate decision maker has to make decisions immediately affecting the adult's end of life situation. The aim of the following is to identify and discuss aspects of section 19 of the HCCF Act (and section 18 in the case of end of life decisions) that pose legal and/or ethical difficulties.

A. Issue IIIa : Does the role to be played by the current wishes of an adult judged to be incapable need to be clarified?

Section 19 presents a conundrum, both ethical and legal, with respect to the role that the current wishes of the adult deemed incapable are to play in the substitute decision making process. On one hand there has been a determination that the adult is incapable of giving, refusing or revoking consent to health care. On the other, the adult will continue to express preferences wishes, or instructions in a wide variety of ways. The Act is committed to the principle, articulated in sections 3(2) and 8, that an adult's way of communicating with others should not affect determinations of the adult's incapability, or the process of receiving instructions when the adult is not deemed incapable. It would appear that that same principle is in effect with respect to consultations the TSDM is required to make with the now incapable adult under section 19(1)(a). The TSDM, in accord with the spirit of the Act, should consult with the adult irrespective of the adult's mode or manner of communication, in a way that is appropriate to that mode or manner.

The difficult question is the weight that should be accorded the incapable adult's current wishes and the way in which they should be factored into the hierarchical decision making process of section 19. Although the TSDM is under a duty to consult with the adult, it is clear, under section 19(1)(b), that instructions or wishes expressed while the adult was capable are to control. Current wishes or preferences, communicated in the course of the consultation process under section 19(1)(a), are to be considered as but one factor, along with "objective" medical factors, in a "last resort" best interests determination.

The most poignant difficulty arises, however, when current wishes appear to be or are clearly at odds with wishes expressed while capable. Should the latter automatically control? If so, what would be the purpose of consultation with the adult? To hold that current wishes should control would of course pose another

dilemma. After all, the adult has been judged incapable. Still a literal reading of the Act would lead to the conclusion that pre-expressed wishes must be complied with unconditionally. Current wishes are to be considered only if there are no known pre-expressed instructions or wishes and the adult's beliefs and values are not known. Even then, insofar as current wishes are included as but one factor in a best interests determination, it would appear that such wishes could very well be subject to the requirement that they be consonant with the adult's best interests.

It may be appropriate to consider whether the current wishes of an incapable adult should be afforded a different role within the hierarchy of criteria set out in section 19. It may be that the drafters, by including the obligation to consult with the incapable adult in the same subsection[18] as the obligation to comply with pre-expressed wishes, intended that compliance with the latter be tempered or qualified by the former. If so, that intention should be clarified. It may also be possible and desirable to accommodate current wishes as a qualifying factor with respect to both pre-expressed wishes in section 19(1)(b) and known beliefs and values in section 19(2).

Method:

1. Consultation with drafters
2. Review of similar provisions in the *Representation Agreement Act* [19] and the *Adult Guardianship Act* ,[20] which provide that the respective surrogate decision makers under each Act are to comply with the adult's wishes if "it is practicable to do so," and consideration of whether the HCCF Act should differ in its treatment of adult's current wishes
3. Review of the relevant medical ethical literature
4. Review of pertinent legislation in other jurisdictions.

B. Issue IIIb : What difficulties exist in practice in ascertaining the instructions or wishes the adult expressed while capable and are there ways to ameliorate those difficulties through legislation?

The abiding principle of patient autonomy extends to what is, in effect, the initial controlling criterion of section 19 of the Act, namely "any instructions or wishes the adult expressed while he or she was capable." Use of the term any underscores the practical, legal and ethical problems deriving from the fact that those wishes might have been expressed under a multitude of different circumstances: in writing or orally, casually or with some degree of reflection or solemnity, at different ages and states of health, and with varying degrees of specificity, to name only a few variables. Various pre-expressed wishes or instructions may even be contradictory. Under what circumstances should pre-expressed instructions be viewed as controlling? Are there circumstances under which the surrogate decision maker should not be obligated to comply with them? How might those circumstances best be articulated? Where those circumstances do obtain, should the pre-expressed wishes or instructions be considered as factors bearing upon the next two hierarchical criteria, known beliefs and values, and best interests? Should that be made explicit in the Act?

In attempting to answer those questions, it is important to bear in mind that section 19 serves both as a guide for surrogate decision makers and as criteria used by the Health Care and Care Facility Review Board, established under section 27 of the Act, in its reviews of decisions to give, refuse or revoke substitute consent to health care. As such, one would not want too complicated or ambiguous scheme for section 19 criteria. On the other hand, a scheme which is too inflexible may fail to reflect the nuances and variability of particular situations in which substitute decisions are made.

As suggested above, the surrogate decision maker faces a serious dilemma in seeking to determine the accuracy, currency or reliability of any pre-expressed wishes, it may be useful to consider whether some provision might be made in HCCF Act section 19 giving presumptive preference for certain types of pre-expressed wishes, or modes of expressing them. Although it would be difficult if not impossible, even were it desirable, to establish a comprehensive scheme of priorities, one might specify certain manners of expressing wishes or instructions while capable, and circumstances under which they were expressed, that should, presumptively, be given greater weight.

This implicates the question of what role instructional advance directives made by the adult while capable should play in British Columbia. British Columbia law currently makes no provision for such directives, commonly referred to as "living wills" both in British Columbia and in other jurisdictions, in many of which they are legally enforceable. *British Columbia's Representation Agreement Act*, also in force as of February 28, 2000, provides only for proxy advance directives. Capable adults may, in a representation agreement, only specify a person whom the adult wishes to have binding and sole authority, subject to certain checks, to decide whether to give, refuse or revoke consent to health care. While the capable adult may give written instructions as to the desired substance of those decisions, either in the representation agreement itself or in some other document or instrument, formal or otherwise, those instructions do not have legally binding force.

One question that might usefully be considered under the rubric of Issue IIIb is whether presumptive priority should be given to certain forms of expression in determining the adult's instructions or wishes expressed while capable. One possibility that might be considered would be instructions or wishes expressed in representation agreements. Having such instructions or wishes would be useful for representatives as well as TSDMs obliged to make decisions if the representative or alternate representative is unavailable or not capable of acting. A provision giving presumptive priority (although not necessarily binding legal force) to such instructions would also, one assumes, encourage adults to make them. Similarly, a provision in section 19(1)(b) of the Act, setting out other forms that would receive preference in determining pre-expressed instructions or wishes (such as "in writing," "notarized," etc.) may also encourage adults to use those vehicles as guides to their surrogate decision makers. Consideration might also be given to the introduction of legally binding "living wills" in British Columbia, either in conjunction with or independent of proxy directives.

Method:

1. Review of legislation in other jurisdictions
2. Consultation with groups involved in education surrounding the use of Representation Agreements
3. Consultation with TSDMs, representatives and others who have made substitute health care decisions for incapable adults under the new legislation.

C. Issue IIIc : Does the notion of the adult's known beliefs and values and the role that they play in substitute health care decision making require clarification?

The next hierarchical criterion, the adult's known beliefs and values, represents an even less reliable basis for making a decision consistent with one that the adult would make himself or herself. There is first the question of how one knows another's beliefs or values. Are they imputed on the basis of personal attributes or self-identification (adherence to certain religions or philosophies, membership in certain organizations, etc.), statements made expressly or implicitly regarding beliefs and values, or from actions taken in

situations posing similar issues, or a combination of all of those?

Further problems arise with respect to the acquisition of such "knowledge." Consideration must be given to the form, time and context of expression of beliefs and values, their currency, the strength of the adult's adherence to them, etc. These are versions of the same problems encountered with respect to pre-expressed wishes or instructions, although amplified all the more because of the general nature of "beliefs and values." That suggests the extremely difficult question of the implications that beliefs and values, even if they can be reliably known, have in terms of specific health care decisions in particular circumstances.

In part the problem of presumed access to such knowledge is addressed in HCCF Act section 16(2), which provides, inter alia, that TSDMs be at least 19 years of age and have been in contact with the adults during the proceeding 12 months. Given those qualifications, the chances would be perhaps somewhat improved that the TSDM would have some idea of the adult's known beliefs and values.

The assumption that TSDMs would have such knowledge can, however, be seriously questioned. In the case of the PGT or its designee, who may serve as the "default" TSDM under section 16(3), it is almost certain that the TSDM will not know the adult concerned. An attempt is made to address that problem under section 19(1)(a)(ii), which requires the employee of the PGT or a person it authorizes to consult with "any friend or relative of the adult who asks to assist." Presumably this could provide the PGT with some information bearing upon the adult's instructions or wishes expressed while capable and/or the adult's known beliefs and values. Again, it is difficult to see how, in most instances, such consultation would lessen the dilemma faced by the PGT, both in terms of the quantity and quality of the information that might be so obtained, and the problems of accuracy and reliability, similar to those noted above as to pre-expressed wishes, compounded by the fact that the information is obtained from a third person.

It may even, in certain cases, be dangerous, in light of the elusive nature of "known beliefs and values," to allow them to be the sole criterion for health care decisions that may bear upon life or death.

Given the difficulties that any TSDM may face in terms of knowing and then giving effect to beliefs and values of the adult in the context of particularized health care decisions, it would appear appropriate to clarify the role that 'known beliefs and values" should play in the process by which a surrogate decision maker decides. Thus one question that might be examined under this issue is whether the 'known beliefs and values" criterion might best be folded into the current section 19(3) as one factor to be considered in determining the best interests of the adult.

Method:

1. Review of relevant medical ethical literature
2. Consideration of pertinent legislation in other jurisdictions
3. Consultation with representatives, TSDMs and others who have been involved in substitute decision making using section 19 criteria.

D. Issue IIId: What role should best interests determinations play, particularly with respect to decisions to refuse or revoke substitute consent to health care necessary to preserve life (substitute decision making at the end of life)?

1. Best Interest Determinations

Section 19 of the Act expressly sets out a best interest determination as an appropriate criterion for TSDMs to follow in deciding whether to give, refuse or revoke consent to health care. For purposes of such decisions made with respect to "health care necessary to preserve life," however, section 18(2) limits legally authorized criteria to pre-expressed wishes or known beliefs and values. Thus, under section 18, a TSDM may not employ a best interests analysis as a basis upon which "to refuse substitute consent to health care necessary to preserve life."

Section 18 poses a number of problems. The first is that it refers only to refusal of consent. The most common end of life decisions involve both refusing consent (that is authorizing the withholding of a particular treatment) and, perhaps more commonly, revoking consent to treatment already begun (for example, the withdrawal from use of a ventilator, feeding tube, or dialysis). Consideration should be given as to whether section 18(2) should be amended to include revocation, as well as refusal, of consent.[21]

The key problem concerning section 18(2) considered here arises from the fact that TSDMs are authorized to make decisions to refuse (again not to revoke) consent to health care necessary to preserve life only on the basis of either pre-expressed wishes or known beliefs and values (the question of requiring that the decision also be 'medically appropriate' is considered under Issue IIIe below). In other words, TSDMs may not use a best interest analysis in making such decisions.

Why should that be the case and how might it be justified? One possible justification would be that, in a situation where the consequence of refusal (or revocation) is the death of another person, that result must be grounded in the autonomous wishes of that person, as known or imputed and carried out by a TSDM. To cross over into the realm of best interests would be, in this analysis, to depart from the principle of autonomy.

Ruling out a best interests basis for substitute decision making in such instances may, however, actually have the effect of compromising the principle of autonomy and the intentions of the Act, specifically the intention to shift the authority and responsibility for health care decisions making away from the health care provider. Let us say, for example, that the TSDM does not know either the adult's pre-expressed wishes or the adult's beliefs and values. In that case, the TSDM would only have authority to consent to the health care, based on a best interest analysis. The best interest analysis could not be used, however, as a basis for refusing consent.

A quandary results. Section 5 of the Act provides that health care can only be given in the absence of the adult's consent when an authorized surrogate decision maker gives consent or, in an emergency as defined in section 12, when such a surrogate decision maker is not available. In the situation under consideration, if a TSDM does not give consent, but cannot refuse consent, what is the health care provider who has proposed the health care supposed to do, and how may the health care provider's decision be legally justified? Does the health care provider become paralyzed in the absence of legally authorized instruction? Or does section 18(2) mean that, contrary to section 5 and basic principles of the common law, the health care provider can give the health care necessary to preserve life, or must give it, based on a Hippocratic notion of beneficence, or a more sophisticated balancing of benefit versus harm (non-maleficence) to the adult, in other words, a best interests determination? How could giving the health care be legally justified? There would be no consent, except if it could be manufactured through a legal fiction under which, for instance, in the absence of authority to refuse, the TSDM must be deemed to have consented.

In such a situation, when the TSDM is not authorized to refuse based on best interests and the health care provider is left with no direction, a basic goal of the Act is contradicted. That is the idea that there will be a

specified individual to serve as a surrogate decision maker for an incapable adult, authorized to make decisions regarding health care. Thus the health care provider is relieved of the responsibility of surrogate decision making which, under the principle of autonomy, should never be within the authority of the health care provider.

In practice, how would (or are) such situations dealt with? On one hand, it could be that health care providers are respecting decisions to refuse health care necessary to preserve life made by TSDMs on the basis of best interest analyses, although such decisions are not legally authorized technically. Perhaps those kinds of "best interests" decisions are expressed in terms of known beliefs and values ("They couldn't have wanted something like this," which may actually mean, "I wouldn't want something like this.").

Alternatively, health care providers could be proceeding with proposed health care without the consent of a TSDM. (The logic would be that, because TSDMs have no authority to refuse in such cases, they must be deemed to have given consent). This is highly unlikely given the possibility of legal liability and the respect in the medical community for notions of autonomy, albeit through surrogate decision makers. The whole point of the Act is that health care providers are not to make the decisions.

Health care providers might also choose to treat the adult's health care needs as urgent or emergent, such that, under section 12, it would be "necessary to provide the health care without delay in order to preserve the adult's life, to prevent serious physical or mental harm or to alleviate severe pain," or to wait until it became so. Under section 12, in those circumstances, the health care could be provided without a TSDM's substitute consent, if other authorized surrogate decision makers were not available or capable of acting. For a health care provider to act in that fashion could involve stretching the definition of urgent or emergency health care (although, except for the modifier "without delay," it is a very broad and malleable definition), or jeopardizing the health of a patient by waiting until action was required without delay. Neither is an acceptable course of action, and it is unlikely health care providers are so acting.

Otherwise, a health care provider could bring the matter to the Health Care and Care Facility Review Board ("the Board") for a review under section 28(c) of the Act, which gives the Board authority to review decisions to give, refuse or revoke substitute consent to health care. A TSDM's refusal of consent to health care necessary to preserve life would, on its face, be reviewable. However, in the situation under consideration, the Board could, it would appear, only rule that the TSDM did not have the authority to refuse consent. It is difficult to see how the Board would have any authority or basis to make a review based on the merits, i.e. best interests, where the TSDM does not have authority to do so. Beyond finding that the TSDM has no authority to refuse, what could the Board do? Could it compel a TSDM to consent on the grounds that the TSDM has no authority to refuse, or could it rule that the TSDM must be deemed to have consented for the same reason? The answer must be no; to do so would violate the spirit, if not the letter of the Act. The conundrum thus would have no resolution.

Do or would such situations arise frequently enough to be addressed or could this apparent anomaly in the Act be tolerated? One suspects that they arise with some measure of frequency. Most people do not record or convey at all their wishes while capable, or fail to do so in a sufficiently reliable or specific fashion. Moreover, even if beliefs and values were known and could be a reliable source for inference as to decisions the adult would make, except if such beliefs and values were strongly and consistently enough held and specifically referable to the particular decision, most TSDMs would not want to rely on them as the basis for a decision that would result in the death of the adult.

In instances, moreover, where the PGT or its designee serves as a "default" TSDM, it is virtually certain that

beliefs and values will not be known. Combined with the fact that most adults do not leave clearly expressed, specific wishes made while competent, in almost all cases that the PGT serves as, or designates a TSDM, it will not have the authority to refuse health care necessary to preserve life. The impact of section 18(2) as it is now written is thus anything but inconsequential.

2. Inclusion of Revocation of Consent

The absence, noted above, of provision in section 18(2) for substitute decisions by the TSDM to revoke consent to health care necessary to preserve life which is being provided, pursuant either to the adult's or the TSDM's earlier consent or an emergency, also presents a quandary. It seems likely that decisions to revoke consent to such health care were intended to be subject to the same restrictions as are placed on decisions to refuse it in section 18(2). Otherwise decisions to revoke consent would fall under section 19(2)(b) and(3), directing use of a best interests determination and specifying factors the TSDM should consider making one. The anomalous result, as between decisions to refuse and those to revoke consent, could not have been intended. If it were, it is difficult to see a justification for it.

Were, however, decisions to revoke consent to health care necessary to preserve life also subject to the restrictions set out in section 18(2), or were made to be so, the practical results would not be consonant with either an appropriate clinical or ethical framework. Take the example, for instance, of an incapable patient suffering from an irreversible condition that will, to the greatest degree of medical certainty, cause death within a matter of weeks. Let us say that the patient is also experiencing intractable pain. The patient is having his or her life maintained by a ventilator, consent to the use of which was properly given. Were the provisions of section 18(2) to apply to revocation of consent, a TSDM who could not base its decision on pre-expressed wishes or known beliefs and values could not revoke consent to the health care, use of which had been legally authorized previously. Unless the health care provider were to make a unilateral decision to withdraw the health care, it would remain in use even if it were medically or ethically inappropriate.

In practice, a health care provider would not act unilaterally. Instead, one would expect consultation with family generally, or a TSDM in particular, resulting in consent to withdrawal of health care and documentation of that consent. Such an approach, consonant, one would think, with good medical and ethical practice, would not be legally authorized in the circumstances. The same would be true for rejection of health care necessary to preserve life.

It is suggested that revision of section 18(2) be considered. It is also suggested, as it was above, that careful attention be given to harmonization of use of the phrase "give, refuse, or revoke substitute consent," or parts of it, in section 18(2) and the entirety of section 19, in light of the aims of the Act.

It is worth noting that section 21 of the Adult Guardianship Act,[22] in common with section 18(2) of the HCCF Act, addresses only refusal, by guardians or substitute decision makers (a specific type of surrogate decision maker under the *Adult Guardianship Act*, not a general appellation), of health care necessary to preserve the adult's life, not revocation of consent to such health care.

Similarly, the Representation Agreement Act, in section 9(c), provides that an adult, in a representation agreement made while capable, may authorize a representative to refuse consent to "specified kinds of health care, including life-supporting care or treatment." No mention is made of revocation of consent. Is this an oversight, similar to other possible oversights in the HCCF Act, the *Adult Guardianship Act* and the *Representation Agreement Act*, or, given the similarity of each on this point, was there an intention to exclude revocation of consent and, if so, why?

Those other provisions may shed light on legislative intentions in the HCCF Act. A consideration of them may also figure in a larger attempt to harmonize and rationalize the scheme pertaining to surrogate decision making at the end of life generally for all surrogate decision makers under the three interrelated statutes.

Method:

1. Review of relevant medical ethical literature
2. Careful study of relevant provisions of the three interrelated statutes and consultation with drafters as to intentions
3.Review of pertinent legislation in other jurisdictions.

E. Issue IIIe: Is there a need to define, or further refine, the concept of "health care necessary to preserve life" as it is used in section 18(2) of the HCCF Act?

In an examination of the need to harmonize the scheme for substitute decision making by the various surrogate decision makers at the end of life, or to clearly articulate differences in the scheme, as between the various types of decision makers, in a rational and justifiable way, another element that should be considered is the definition of "health care necessary to preserve life." As previously noted, it is amenable to a very broad interpretation, covering an extensive range of health care. It may include the most straightforward and relatively non-invasive of surgical procedures, or complex surgery entailing great potential risk. It may also include so-called "life-supporting care or treatment" which implies treatment that is not intended to, nor can result in a "cure" or amelioration of an underlying medical condition, but is merely "keeping alive" someone who would die within a relatively short time of withholding or withdrawal of the care or treatment.

Given the vast possible differences in the medical and ethical considerations surrounding those various categories of health care, all of which could fit into a definition of "health care necessary to preserve life," is there a need to differentiate as to their legal treatment with respect to surrogate decision makers' authority to refuse (or revoke) consent to them? The issue of an appropriate definition of such health care, or of subcategories thereof, is related to consideration of a rational and justifiable scheme, calibrated to those definitions, differentiating the authority to refuse or revoke consent to such health care, as among the various types of surrogate decision makers, together with any restrictions upon that authority, the processes available for review of those decisions, and the criteria to be applied in such reviews. It would appear that that kind of integrated approach is lacking in the current set of interrelated statutes.

For instance, the *Representation Agreement Act* differs in its description of the health care to which consent may be refused by a representative. That Act refers, as noted above, to "specified kinds of health care, including life-supporting care or treatment." Does the particular wording in that Act mean that an adult cannot give a representative, designated personally by the adult, authority to refuse consent to health care necessary to preserve life generally, even though surrogate decision makers under the *Adult Guardianship Act* , appointed by a court, and the HCCF Act, selected from a list set out in the statute, have that authority?[23] This would appear to be an inconsistency of some consequence, contrary to the emphasis on personal autonomy of the adult that undergirds all of the related statutes.

Any study reviewing inconsistencies or other difficulties related to section 18 of the HCCF Act should also embrace a review of the general scheme regarding authority to make surrogate decision at the end of life as set out in all three statutes, including refinement of the notion of "health care necessary to preserve life."

Method:

1. Careful review of all relevant provisions in the interrelated statutes
2. Consultation with drafters as to intentions
3. Review of pertinent legislation in other jurisdictions with regard to more refined definitions of health care or treatment which, if not provided, will lead to the incapable adult's death and implications for the rights and duties of surrogate decision makers.

F. Issue IIIf : Is there a need to reconsider the powerful role accorded to health care providers' judgments as to the "medical appropriateness" of TSDMs' refusals of consent under HCCF Act section 18(2)?

Despite inconsistencies, there does appear to be a hierarchy of authority in place already in the three statutes as among the various types of surrogate decision makers with respect to refusal of consent to health care necessary to preserve life. Guardians, substitute decision makers and TSDMs are restricted to pre-expressed wishes and known beliefs or values as bases for making such a refusal. Representatives may only be authorized to refuse care to specified kinds of health care, but need not make reference to any basis for that refusal insofar as it merely implements express wishes of the adult made while capable. That greater authority for representatives appears to be balanced by lack of authority to refuse consent generally to health care necessary to preserve life, based on any criteria.

TSDMs are subject, under section 18(2)(a) of the HCCF Act, to another restriction on their authority to refuse consent to health care necessary to preserve life. That section provides that even if the TSDM's refusal is based on an allowed criterion, it may not be carried out unless "there is substantial agreement among the health care providers caring for the adult that the decision to refuse substitute consent is medically appropriate" (emphasis added).

On one hand that restriction, not applied to guardians or substitute decision makers under the *Adult Guardianship Act*, ensures that TSDMs will consult with the health care team before making a decision. That aspect is not problematic; in fact it promotes a desirable end. However, the provision also gives to the health care providers an effective veto over the TSDM's decision. That veto, moreover, is based upon an indefinite and rather flexible criterion ("medical appropriateness") that bespeaks the medical paternalism that the Act seeks to diminish, if not eliminate.

It would appear that the "medical appropriateness" restriction gives to health care providers the authority to bring what amounts to a non-reviewable best interests determination to bear upon a decision whether to provide health care necessary to preserve life, a criterion the TSDM is prohibited to rely upon. The provision thus raises both ethical questions, in light of its apparent sanction of a medically paternalistic approach, and legal questions, in light of the Act's avowed promotion of self-determination and autonomy. Can the provision be justified?

Let us say that a TSDM makes a decision to refuse health care necessary to preserve life based upon clear evidence of the adult's pre-expressed wishes. Should the health care providers be allowed to override that decision based on "medical appropriateness"? Presumably any determination of the latter would entail consideration of the factors, set out in section 19(3) of the HCCF Act, that a TSDM must consider when authorized to make a best interests judgment, such as the likelihood of improvement with or without the health care, the relative benefit and harm to be expected from the health care, etc. Thus, the health care providers in this situation would be authorized to rely, in effect, upon best interest criteria (denied to the

TSDM in all cases of refusal of consent to health care necessary to preserve life), in order to supersede the pre-expressed wishes of the adult. The result is clearly inconsistent with the purposes of the Act in its grant of paternalistic authority to health care providers.

It is also, moreover, an open question whether the health care provider's judgment as to medical appropriateness would be subject to review. Under section 28(1)(c) of the Act, the HCCF Review Board has the authority to review "a decision to give, refuse or revoke substitute consent to health care." Health care providers' judgments as to the medical appropriateness of withholding (or withdrawal) of health care are not decisions to give, refuse or revoke substitute consent and would not, it appears, fall within the Board's jurisdiction.

It would seem appropriate to examine the role that health care providers' judgments as to "medical appropriateness" should play in end of life substitute decision making.

Method:

1. Review of relevant medical ethical literature
2. Consideration of the overall scheme for substitute decision making at the end of life set out in the three interrelated statutes, and
3. Review of legislation in other jurisdictions as to the role judgments as to medical appropriateness play in relation to judgments made by surrogate decision makers.

IV. Do Not Resuscitate Orders and Levels of Care Instructions

Issue IV: Is there a need to consider a legal scheme under which do not resuscitate orders (DNR orders) and levels of care instructions are made subject to the same respect for autonomy and self-determination, and the clearly delineated authority of surrogate decision makers that characterizes the HCCF Act and related legislation?

A. Issue IVa: Are DNR orders and levels of care instructions subject to the provisions of the HCCF Act?

Upon entry into any long term care facility in British Columbia, instructions as to the "levels of care" are put into the medical record of the person admitted. Those instructions, or directives, affect the health care that person will receive in future in the event of (unspecified) health care eventualities. In that sense, they are advance directives. One example of levels of care instructions for someone admitted, for instance, into a nursing home, would be as follows:

1. Comfort care only.
2. Care within the institution only (depending on available facilities, may include antibiotics, use of IVs, etc., and some minor interventions).
3. Transfer to an acute care facility, but no admission to ICU (Intensive Care Unit) and/or no CPR (cardiopulmonary resuscitation).
4. All possible interventions, including CPR.

A patient, upon admission, or the patient's surrogate, would choose, or the patient would be assigned, a level of care. The exact terms used in levels of care instructions, as well as the number of levels, their content and even the numbering of levels are apparently neither standardized nor consistent within the province.

In addition, either as part of a levels of care instruction or a separate document, a DNR order may also be entered into a person's medical record upon admission to a long-term or acute care facility or at a subsequent time. Ostensibly, DNR orders mean that in the event of heart failure, CPR will not be attempted. In part, perhaps, because of less than thorough education among health care providers, lax practice or inferences drawn from the presence of a DNR order in the medical record, the effect of a DNR order may be extended beyond CPR. Health care providers may take it to mean that reduced levels of care are indicated generally.

Thus, levels of care and DNR orders have profound impact on the health care that a person will receive. The principle of autonomy in health care would seem to suggest, perhaps even demand, that the wishes of the adult concerned or that adult's legally authorized surrogate decision maker should play a prominent, if not controlling, role in the formulation of such health care directives. The immediate question to be addressed, then, is whether the authority and rights of TSDMs (or for that matter competent adults) under the HCCF Act may be exercised with respect to levels of care directives and DNR orders. In other words, does the Act apply to those types of health care decisions?

Arguments can be made either way. The most compelling argument supporting the view that the Act does not apply derives from the Act's definitions set out in section 1. There, "health care" is said to mean "anything that is done for a therapeutic, preventive, palliative, cosmetic or other purpose related to health."[24] DNR orders and levels of care instructions, the argument goes, relate to things that will not be done (or non-actions). Thus the right to give, refuse or revoke consent to health care does not embrace a right to do so with respect to DNR orders and levels of care instructions.

The syllogism is a tight and perhaps compelling one, but can be met on its own turf. The Act does authorize the refusal and the revocation of consent and substitute consent. Refusal of consent can be viewed, in one sense, as consent to (or even a directive to perform) a non-act: the non-provision, or withholding of what we will call "treatment," to avoid the pitfalls of the contentious term "health care." The same is true of revocation of consent, which constitutes consent to (or again a directive to perform) a non-act: withdrawal, or cessation of treatment. In each case, it is the adult or the TSDM who is directing performance of a non-act, the non-provision of treatment.

Returning to the definition in section 1, because the Act recognizes refusal and revocation of consent, which by their very nature are directions not to perform, the scope of things done under the definition of "health care" must include things not done. The idea comports with common sense. A health care provider who chose, at the direction of an adult or a TSDM, or even on his or her own volition, not to provide a particular treatment because it would not have, or was no longer having a therapeutic result, would be doing something for a therapeutic purpose. Arguably, that action (of not providing) could not, under section 5 of the Act, be performed without consent of the adult or a legally authorized surrogate decision maker, or in an emergency.

This argument can obviously be challenged, perhaps by a more logical one. But, even if the argument developed in the previous two paragraphs were found to be persuasive, one wonders whether this type of argument (and the counter-argument is of the same type) should be determinative of whether the HCCF Act applies to DNR orders or levels of care instructions, and even more importantly whether the latter types of advance directives should be applied to patients without their consent or that of their surrogate decision makers.

There is another argument, based on the informed consent requirements of the Act, that can be posited

contrary to the proposition that DNR orders and levels of care instructions can be imposed without consent (or at least that there are no consent rights under the Act) because they do not involve acts that are done (i.e. they direct non-action) and thus do not constitute "health care." Section 6(e) of the Act purports to codify the common law doctrine of informed consent, setting out the information that a health care provider must give to the adult (or the TSDM, under sections 10 and 17(6)) in the course of obtaining consent. Section 6(e)(iv) provides for explanation of "alternative courses of health care" to the one proposed. Under the case law, it has been clearly established that those alternatives include doing nothing (i.e. no treatment). Decision makers have the authority to consent to the alternative of non-action, something that is not done. Corollary to that, a health care provider could not exercise the option of doing nothing unless the adult or a surrogate decision maker had consented to that act of not doing.

Thus it would appear that not taking action can be something done for purposes of the Act. Still that does not necessarily mean that DNR orders and levels of care instructions are subject to the Act in the sense that, because of the Act, they could not be imposed, or "written" as it is said, unless the adult or the surrogate decision maker consented.

The reason that section 5 (requiring consent for all "health care"), section 6 (requiring, inter alia, communication of alternative courses of "health care," including non-action, in the course of obtaining consent) and section 10 (applying section 6 to instances where consent is to be given or refused by surrogate decision makers) taken together do not necessarily mean that DNR orders and levels of care instructions are subject to the Act is because the Act appears to be founded on the notion that consent is required only for health care that is proposed by the health care provider for specific health care conditions (section 6 refers to "the proposed health care"). This is the context within which the common law doctrine of informed consent, codified in the Act, developed. Going beyond the basic doctrine of liability in battery for a specific act of "touching" without simple consent, the doctrine of informed consent imposed a duty of disclosure and explanation with respect to that specific act of proposed health care (which again may include doing nothing, or non-action) in response to a specific health condition affecting a patient.

The problem with DNR orders and levels of care instructions is that they do not refer to specific acts of health care proposed for a particular existing condition."[25] They are general treatment directives to be applied should a particular health condition (cardiac failure in the case of DNR orders) or a range of unspecified conditions (potentially any serious health condition in the case of levels of care) arise in future. In that sense they do not fit within the mold of medical decision making arguably contemplated and addressed by the HCCF Act (although again arguments could be made the other way).

Ironically, were a health care provider to choose to present or propose the various choices and treatment options contained in a DNR order or levels of care instruction to the adult or surrogate decision maker and the conditions under which certain types of health care would be given and others not (the latter would constitute an "alternative course of health care," i.e. providing no treatment), it could be argued, quite convincingly, that consent would be required before the DNR order or levels of care instruction was entered into the medical chart. For example, the health care provider could say to a surrogate decision maker for an adult admitted to a log-term care facility, "Should the adult experience cardiac arrest, there are a number of options, including CPR," and then explain the risks entailed in CPR (which are considerable, especially for frail or elderly patients). The surrogate would then make a choice. A DNR order could not be placed in the patient's chart unless the surrogate decision maker consented.

That would seem to be consistent with the policy of the Act as expressed in section 4(e) that "every adult who is capable of giving or refusing consent to health care has the right to involved to the greatest degree

possible in all case planning and decision making."[26] This would seem to grant a right, which includes a derivative right exercisable by surrogate decision makers, above and beyond the giving and refusing of consent to health care, whatever view one takes as to the scope of the latter's definition under the Act. Few would argue that DNR orders and levels of care instructions, which are general advance directives, planning documents that literally will determine the life or death of a patient, do not constitute a form of "case planning and decision making." Section 4 of the Act seems to establish case planning and decision making as a category distinct from "health care" and to grant a right of involvement to the greatest degree possible in their formulation. Whether the "right to be involved" embraces the right to give or refuse consent is, of course, a matter for debate.

To allow the applicability of the Act (and the rights it affords to adults and their surrogate decision makers) with respect to DNR orders and levels of care instructions to depend upon whether health care providers present them as "proposed" health care or not is to abandon the very principle of autonomy embodied in the Act and to revert to medical paternalism.

Still, it does not appear that an incontrovertible legal conclusion can be drawn as to whether the HCCF Act applies to DNR orders and levels of care instructions. Indeed the Chair of the HCCF Review Board has recently held that the Board does not have jurisdiction to review imposition of DNR orders because they do not constitute "health care" as defined in the Act. The Act does not expressly refer to DNR orders or to levels of care instructions. To hold that an Act not expressly designed (it would appear) to deal with them applies to them could conceivably cause as many problems as it solves. As described below, there is a clear need for legislative approaches to DNR orders and levels of care instructions that respect the rights of capable adults and the derivative rights of surrogate decision makers. It is not at all clear though that forcing them within the rubric of the HCCF Act as it currently stands is the proper means to that end.

There is strong anecdotal evidence that a number of health care providers do write DNR orders and place them in medical charts unilaterally. If the HCCF Act does not require consultation and involvement in decisions regarding CPR (or to put it another way, the placement of DNR orders), or does not require that DNR orders and levels of care instructions have to be accepted or rejected by patients or their surrogate decision makers, is there any binding case law determinative of this question?

There have been no British Columbia cases addressing the issue. In the scant case law from other Canadian jurisdictions, consisting of two cases from Manitoba and one from Ontario, there has not been found a right on the part of patients or their surrogate decision makers to give or refuse consent to DNR orders that would necessarily prevail over the opposing views or actions of health care providers.

In one of the cases, Child & Family Services of Central Manitoba v. R.(L.),[27] the Manitoba Court of Appeal, in a brief opinion, upheld the actions of a physician who had placed a DNR order, over the objections of the parents, on an 11 month-old infant who was in a persistent vegetative state as the result of an assault. The parents were, it appears (although not in the text of the judgment), suspects in the assault. Their motive for seeking CPR and the continued life of the child, moreover, is said to have been for the child to survive longer than one year from the time of the assault for purposes of reduced charges under the Criminal Code.

The Court stated that "the wishes of the patient's family or guardian should be taken into account, but neither their consent nor the approval of a court is required."[28] The facts of R.(L.) were extreme. The treatment concerned would be, by any reasonable definition, medically inappropriate and the surrogate decision makers were clearly not motivated by the best interests of the patient, but by their own self-serving

ends. In such a case, it comports with common sense to say that the wishes of the parents should not prevail as a matter of right. The Court, in holding that the parents' consent is not required, may be saying no more than that.

Certainly by saying that the wishes of the family should be taken into account, the Court is implying that there should be consultation with the family. It is an open question whether the case stands for the proposition that health care providers can, in all cases, unilaterally place DNR orders, although some appear to have taken it that way.

In the case of Sawatzky v. Riverview Health Centre Inc.[29] the Manitoba Court of Queen's Bench did not appear to support such a broad, unqualified interpretation of R.(L.). Sawatzky involved an application for a preliminary injunction by the wife of a 79 year old man, who had severe Parkinson's disease along with other ailments, seeking to have nullified a unilateral withdrawal, by the treating physician, of an order to provide CPR that the physician had previously placed. The injunction was granted and the act of the physician, which had the effect of placing a DNR order on the patient, was nullified pending trial of the case. Mr. Sawatzky died before the case could be tried on its merits.

The Court, it should be noted, did not rely on R.(L.), and its supposed recognition of physician's unilateral authority to place DNR orders over the objection of surrogate decision makers. The question was, however, complicated by the fact that Mrs. Sawatzky claimed that her husband was capable and that she was merely transmitting his wishes. Thus the question of overriding a surrogate decision maker's objection, decided in R.(L.), may not have been faced in Sawatzky had it been tried. It should be noted that Mrs. Sawatzky had been replaced as surrogate decision maker by the public trustee, who was excoriated by the Court for failing to appear in the case. The Court stressed that the placement of a DNR order over the objection of a patient was a matter involving the public interest, not merely one between patient and physician.

Even though the issue may be a matter of public interest, the *Ontario Court of General Division in London Health Sciences Centre* v. *K.(R.)* (Litigation Guardian of)[30] declined to issue a declaration that placement of a DNR order by the treating physician and hospital on an 83 year old patient in a persistent vegetative state, over the objection of his spouse, was legal.

Thus, except for the R.(L.) case, with its extreme set of facts, no Canadian courts have ruled dispositively on the question of whether health care providers may unilaterally write DNR orders, either without consulting with, or over the objections of, a duly authorized surrogate decision maker. The courts have yet to rule on the respective roles of health care providers and surrogate decision makers with respect to the placement of DNR orders or levels of care instructions. Certainly, there is no controlling judicial authority in B.C.

B. Issue IVb: Is there a need for legislation in British Columbia regulating the placement of DNR orders and levels of care directives?

There are a number of difficulties surrounding the use of DNR orders and levels of care instructions, instruments which, as was seen above, are of utmost importance in end of life planning. One of them entails their unilateral placement by health care providers, or placement without adequate consultation or understanding. It is said that physicians in Manitoba, for instance, and perhaps elsewhere, including British Columbia, view R.(L.) as judicial sanction for unilateral placement of DNR orders. That in and of itself would militate toward some sort of legislative act addressing the problem, particularly given the right, under section 4(e) of he HCCF Act to be involved to the greatest degree possible in all case planning and decision making.

There are other difficulties. Whether placed unilaterally, without adequate consultation, or even with such consultation, DNR orders and levels of care instructions may stay in medical charts for undue lengths of time (which could, depending on the circumstances be years, months, or even weeks or days) without review in light of changed health conditions or preferences.

DNR orders and levels of care instructions may not necessarily be portable from one institution to another. For instance, a levels of care instruction carefully worked out after full consultation between health care providers at a chronic care facility and surrogate decision makers might be superseded by new directives imposed under emergency circumstances should the patient be transferred and admitted to an acute care facility. Parents of persons with disabilities, for instance, report that this does occur.

It also appears that even the content and numbers attached to different levels of care at various facilities around the province are not uniform, another obstacle to careful planning that will be respected by different health care providers caring for the same person.

Because of the practice of assigning levels of care at the time that a patient is admitted into a facility, even if there is discussion and consultation regarding those directives, the discussion may occur at times of the most extreme stress for decision makers, making full understanding and agreement even more difficult to attain. If the directives entered into the chart are not revisited, the results of what can only be described as an unsatisfactory process are enduring, affecting the provision of health care profoundly.

There are, however, countervailing reasons militating against full control by surrogate decision makers over end of life treatment decisions. By refusing to consent to the withholding of certain types of health care, such as would be set out in a DNR order or levels of care instruction, surrogate decision makers would in effect be requesting, proposing, or even demanding certain treatments or types of health care. The informed consent model, founded on health care providers proposing treatments and alternatives, and decision makers giving, refusing or revoking consent to what the health care providers propose, would be, depending on one's point of view, either reversed or expanded.

The prospect of patients or their surrogate decision makers dictating the content of medical treatment, rather than having controlling authority over that which is proposed to them, raises two legal, ethical, and ultimately social concerns. The first is potential impingement upon health care providers' prerogative, or right (in addition to their ethical obligation) not to provide health care they have judged to be medically inappropriate. A common situation where conflict could arise between patients' or surrogates' insistence on treatment and health care providers' right or obligation not to provide it is when the health care providers have adjudged the treatment to be "futile." The term, the concept it represents and whether it applies in any given situation are controversial, both in law and in ethics. Still it may be a key concept figuring in any balancing of patients' (and surrogates') rights, or powers, to stipulate or control the content of medical treatment as against the rights or obligations of health care providers.

A second concern is the overriding fact that health care resources are limited. Especially with scarce, high cost treatment modalities (frequently employed at the end of life as well as in other acute care situations), use of the treatment for one person means that another person will be denied its use, which may lead to a worsening of the second person's condition, or even death. How to choose between the two potential recipients poses the most profound of dilemmas, as does justifying any criteria employed. (Thus the term "futile," sometimes used as a rationalization for the denial of health care, has a resonance that goes far beyond "objective" scientific determinations supposedly embraced in the term. For many, the term and its

application are quite embroiled, implicating issues that bear upon such matters as judging the quality of life of individuals or classes of people, as well as any number of religious, community and other values).

The fact that allowing patients or their surrogates to dictate the medical treatment offered and provided to them gives rise to the difficulties discussed above does not mean, however, that control over what is offered and provided should rest solely or ultimately with health care providers. Such control would run counter to the principles of autonomy and self-determination, which have come to be the central principles informing the law, ethics and practice surrounding medical decision making and the patient-physician relationship.

As suggested above, control does not have to fall to one or the other "side." A balance between the two may be possible, taking into consideration the values (health care providers' rights or obligations and the appropriate allocation of scarce health care resources) that may be jeopardized by fully autonomous choice exercised by patients or their surrogates.

The most appropriate vehicle for defining and effecting such a balance would be legislation. The current HCCF Act does not expressly address DNR orders and levels of care directives. It is not clear, as shown in the discussion above, whether its general principles and specific provision apply to them. The Act contains only one provision, section 18(2), that addresses even one small subset of questions involving the balance of decision making authority at the end of life as between surrogates and health care providers. In that provision, health care providers are given ultimate say, it would appear, as to whether the refusal of health care necessary to preserve life may be refused by a surrogate decision maker, on the basis of whether the refusal is "medically appropriate."

If the best way to address problems surrounding the use of DNR orders, levels of care instructions, or other forms of general advance health care directives is legislation, does it make sense to approach that goal through amendment of the HCCF Act? An initial response would be no. The Act as it stands is, in the view of many, and perhaps as demonstrated even in the discussion of issues treated in this document alone, an extremely complicated piece of legislation, many aspects of which have yet to be resolved. To freight it with provisions dealing specifically with the use of DNR orders and levels of care instructions may overburden the Act even more, at the same time working against the clarity one would wish in setting out provisions regarding DNR orders and levels of care instructions. It simply does not appear that problems surrounding them could be best be addressed within the framework, the vocabulary and the concepts of the current HCCF Act.

A study considering the possibility of separate legislation in this area, with recommendations as to the content of such legislation would appear to be in order. There is precedent for stand-alone legislation addressing DNR orders. For example, each U.S. state, it is reported, has laws addressing the placement of DNR orders, balancing the rights and obligations of patients (and their surrogates) on one hand and health care providers on the other, and providing mechanisms for the resolution of disagreements that arise. It is difficult to see how such a comprehensive scheme could be fitted into the current HCCF Act, although the possibility of a separate Part of that Act might be one alternative considered.

A similar study concerning levels of care instructions would also appear appropriate. Again, an approach that balances the roles of patients (and their surrogates) and health care providers would appear to be desirable. Such an approach would encourage, or mandate full consultation, review at appropriate times and, to the extent possible, the presentation of health care alternatives with respect to specific health care conditions as they arise, rather than general directives that purport to cover responses to any number of possible eventualities in advance.

Method:

1. Review of the legal and ethical literature
2. Review of existing and proposed legislation in other jurisdictions, and
3. Consultation with appropriate groups and individuals.

V. Dispute Resolution and the HCCF Review Board

Issue V: What mechanism should be in place for the resolution of disputes relative to health care decision making by or on behalf of individual adults, and what role should the Health Care and Care Facility Review Board play in it?

The Health Care and Care Facility Review Board ("The Review Board" or "the Board") was established under section 27 of the HCCF Act. Although as passed, section 28(1) of the Act gives the Board authority to review seven categories of decisions related to health care, because most of section 28 has not been proclaimed, the only review authority the Board currently has is, under section 28(1)(c), with respect to "a decision to give, refuse or revoke substitute consent to health care."

A. Issue Va: What is or should be the subject matter jurisdiction of the Board?

One question arising out of the wording of section 28(1)(c) is whether the Board has the authority to review decisions to give, refuse or revoke consent to DNR orders and other forms of general advance directive instruments propounded by health care providers, including levels of care instructions. Although there are arguments on both sides of that question, some set out above in discussion under Issue IV, the Board Chair has recently held that the Board does not have jurisdiction to conduct such reviews because the instruments in question are not embraced within the definition of "health care" under the Act.

Should the Board have jurisdiction to review such decisions? The approach to and resolution of that question will depend on a number of factors, including whether the Act is deemed to apply those types of decisions. It is also possible that, if a separate law is put in place regulating the placement of DNR orders and similar instruments and it contains a mechanism for dispute resolution, the Board, or a similar body might serve as part of that mechanism. The answer to the question thus hinges on the development and the nature of a comprehensive legislative scheme to deal with the broadest range of medical treatment decisions by and for individual adults. Thus any examination of that question would have to be linked to consideration of an overall scheme, especially were the view to prevail that DNR orders, levels of care instructions and other similar instruments are not within the purview of the HCCF Act.

B. Issue Vb: Does or should the Board have jurisdiction to review decisions by surrogate decision makers other than TSDMs?

Another question related to the scope of the Board's authority is whether it may review decisions made by surrogate decision makers other than TSDMs. The HCCF Act takes account of other surrogate decision makers, including representatives, guardians and substitute decision makers, designated by the adult or a court under the *Representation Agreement Act* and *Adult Guardianship Act respectively*.

One immediate problem that has arisen with respect to the jurisdiction of the Board has to do with whether it has the authority to review decisions to give, refuse or revoke consent made by committees of the person appointed under the *Patients Property Act* .[31] The latter Act remains in effect pending full proclamation of

Part 2 of the *Adult Guardianship Act*, which provides for the appointment of, and other matters related to, decision makers, guardians and monitors. Reflecting the fact that that Part has not been proclaimed, the HCCF Act, in section 1, defines "guardian" to include committees of the person. Those committees are in place and are making health care decisions on behalf of patients.

What happens if someone objects to a health care decision made by a committee of the person? One view would be that the HCCF Review Board can and should review the decision under section 28(1)(c) of the HCCF Act. The opposing view, and the one that apparently now prevails, is that the Board is authorized to review decisions made pursuant to the Act, which deals expressly only with decisions made by TSDMs and the criteria therefor. Criteria for decisions by committees are not provided for in the HCCF Act, nor, for that matter, in the *Patients Property Act*. Indeed the view has also been expressed that the *Patients Property Act* does not even clearly grant committees of the person authority to make health care decisions.

If the HCCF Review Board does not take jurisdiction over health care decisions made by committees of the person on behalf of incapable adults ("patients" as defined under section 1 of the *Patients Property Act*), how might they be reviewed? The answer would appear to be through recourse to the Supreme Court of British Columbia under parens patrie powers, a mode of review that is awkward at best. It is not clear that that is an alternative preferable to review by the Review Board. It is suggested that one question that might be included in any study bearing on the role of the Review Board is whether, as a provisional matter until Part 2 of the *Adult Guardianship Act* is put in force, the Board's jurisdiction should expressly be made to extend to decisions made by a committee of the person.

There is another, larger question that might figure in a study of the Board's role in review of health care decision making outside the boundaries of the HCCF Act. As legislation now stands, if there are objections regarding decisions made by representatives under the *Representation Agreement Act* , those are to be made to the PGT, which is to investigate them and, if appropriate, raise them before the Supreme Court of British Columbia.[32] If and when Part 2 of the *Adult Guardianship Act* is proclaimed, objections concerning guardians or substitute decision makers will have to be made upon application directly to the court.[33]

The range of acts concerning which the court may consider objections under both of the latter Acts extends significantly beyond health care decisions. Similarly, remedies the court may implement, including removal of surrogate decision makers, revising or revoking a representation agreement or changing a court order appointing or changing a court order appointing a guardian or substitute maker,[34] are not finely calibrated to deal with the disposition of disputes regarding particular health care decisions.

An application for review made directly to the court may be seen as more cumbersome and, for many members of the public, more daunting, than an application made to a body such as the HCCF Review Board. In the case of a representative's acts, objections are made to the PGT, although recourse must be had to the ultimate dispositive authority of the court, again with its set of remedies that are not necessarily suited to resolution of disagreements regarding health care decisions.

The HCCF Review Board, as conceived in the HCCF Act, is, by contrast to the British Columbia Supreme Court, a specialized body possessing relevant expertise whose procedures are both expeditious and protective of the rights of all concerned. It is constituted under the HCCF Act, which deals specifically and exclusively with decisions relative to health care, as opposed to the *Representation Agreement Act* and *Adult Guardianship Act*, which address the broadest possible scope of surrogate decision making. Moreover, the Board has, or, one expects, will develop considerable expertise in interpreting and applying the criteria for health care decision making set out in section 19 of the HCCF Act. Essentially the same criteria apply to the

surrogate decision makers who do and will act under both the *Representation Agreement Act* and the *Adult Guardianship Act* (when and if the relevant sections of the latter are proclaimed).

Thus it would be appropriate to examine whether the HCCF Review Board can play a comprehensive role in reviewing substitute consent to health care made by any of the various surrogate decision makers in place and contemplated under the various relevant Acts.

It is recognized that the overall scheme for substitute decision making for adults generally, under the complex and interrelated statues discussed here, has neither been finally settled nor implemented. It is also likely that there is now, or will shortly be, underway a review of the jurisdiction, operations, administrative structure and other aspects of the Review Board. The question of the Board's ultimate role cannot be approached in isolation. As noted that role, and even the way in which an examination of that role should be approached, will depend on the resolution of a number of other issues.

Postscript - A Note on Methods Proposed Herein

Many of the issues discussed in this document involve closely interrelated matters touching upon both legal and ethical concerns. The methods proposed for examination of many of the issues include review of both the relevant ethical and legal literature and consideration of matters raised in each, and particularly questions as to their interrelationship. It is suggested that further study of issues discussed in this document that involve ethical elements be conducted by a research team composed of at least one legal expert and one expert in health care ethics.

Many of the methods for study proposed herein also include consultations with affected groups or individuals, or those possessing particular expertise or experience. It is suggested that judgments as to whether consultations with groups or individuals involved in implementation of the HCCF Act or other acts would be useful may be made in conjunction with a body such as the HCCF Act Planning Group, as might identification of appropriate groups or individuals to be consulted with in regard to any particular issue.

Appendix A

Re: Terms of Reference - Health Care Decisions and End-of-Life Issues

This letter is to confirm that the Public Guardian and Trustee of British Columbia will contribute to the BC Law Institute for the development of Terms of Reference for a study that will address but not be limited to the following:

Explore health law issues related to the *Health Care (Consent) and Care Facility (Admission) Act* with particular attention to substitute health care decision making as it applies to end of life issues

> Identify legal and ethical dilemmas within the substitute decision making provisions of the Act
>
> Consider the concept of the "patient's best interests" in the context of the comatose patient
>
> Consider the appropriate division of decision making between health care providers and other decision makers in the context of proposals to treat and proposals to withhold or withdraw treatment
>
> Consider the role, jurisdiction and functioning of mechanisms to resolve disputes

Consider the extent and nature of consultation to be undertaken for purposes of the study and the process that should be adopted

With the implementation of the Adult Guardianship Legislation, and in particular the *Health Care (Consent) and Care Facility (Admission) Act*, issues have arisen where there is not a common understanding of the provisions in the legislation, and which are not easily resolved with the development of policies and procedures.

The purpose of this project is to develop Terms of Reference to identify the issues and describe a process for discussion and clarification. During the development of the Terms of Reference, we look forward to discussions that would include an informational meeting with the members of the Health Care (Consent) and Care Facility (Admission) Planning Group of the Public Guardian and Trustee.

We look forward to your work in this important area of health law.

Appendix B

Health Care (Consent) and Care Facility (Admission) Act

R.S.B.C. 1996 Chapter 181

As amended by:

Adult Guardianship Statutes Amendment Act, S.B.C. 1999, c. 25

Definition of Spouse Act, S.B.C. 2000, c. 24

Adult Guardianship Statutes Amendment Act, S.B.C. 2001, c. 2

Part 1 - Introductory Provisions

Definitions

1 In this Act:

"adult" means anyone who has reached 19 years of age;

"board" means a Health Care and Care Facility Review Board established under section 27 (1);

"care facility" means

(a) a facility licensed under the *Community Care Facility Act* and regulated under the Adult Care Regulations, British Columbia Reg. 536/80,
(b) a private hospital licensed under Part 2 of the *Hospital Act*,
(c) an institution designated as a hospital under the *Hospital Act* for the treatment of persons referred to in paragraph (b) or (c) of the definition of "hospital" in that Act, or
(d) any other facility, or class of facility, designated by regulation as a care facility;

"court" means the Supreme Court of British Columbia;

"designated agency" means a public body, organization or person designated as an agency under section 61 (a) of the *Adult Guardianship Act* for the purposes of Part 2 of that Act;

"facility care proposal" means a proposal described in section 20 (1);

"guardian" means a person appointed as

(a) a guardian under the *Adult Guardianship Act*, or
(b) a committee of person who is declared under the *Patients Property Act* to be

(i) incapable of managing himself or herself, or
(ii) incapable of managing himself or herself and his or her affairs;

"health care" means anything that is done for a therapeutic, preventive, palliative, cosmetic or other purpose related to health, and includes

(a) a course of health care, for example, a series of immunizations or dialysis treatments or a course of chemotherapy, and
(b) participation in a medical research program approved by an ethic committee designed by regulation;

"health care provider" means a person who, under a prescribed Act, is licensed, certified or registered to provide health care;

"major health care" means

(a) major surgery,
(b)any treatment involving a general anesthetic,
(c)major diagnostic or investigative procedures, or
(d)any health care designated by regulation as major health care;

"minor health care" means any health care that is not major health care, and includes

(a) routine tests to determine if health care is necessary, and routine dental treatment that prevents or treats a condition or injury caused by disease or trauma, for example,

(i) cavity fillings and extractions done with or without a local anesthetic, and

(ii) oral hygiene inspections;

"representation agreement" means an agreement made under the *Representation Agreement Act*;

"representative" means a person authorized by a representation agreement to make or help in making decisions on behalf of another and includes an alternate representative;

"spouse" means a person who

(a) is married to another person, and is not living separate and apart, within the meaning of the *Divorce Act* (Canada), from the other person, or (b) is living and cohabiting with another person in a marriage-like relationship, including a marriage-like relationship between persons of the same gender;

"substitute decision maker" means a person appointed under the *Adult Guardianship Act* as a substitute decision maker.

1993-48-1.

Presumption of capability

3(1) Until the contrary is demonstrated, every adult is presumed to be capable of

(a) giving, refusing or revoking consent to health care, and
(b)deciding to apply for admission to a care facility, to accept a facility care proposal, or to move out of a care facility.

An adult's way of communicating with others is not, by itself, grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1).

1993-48-3.

Part 2 - Consent to Health Care

Consent rights

4 Every adult who is capable of giving or refusing consent to health care has

(a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death,
(b)the right to select a particular form of available health care on any grounds, including moral or religious grounds,
(c)the right to revoke consent,
(d)the right to expect that a decision to give, refuse or revoke consent will be respected, and
(e)the right to be involved to the greatest degree possible in all case planning and decision making.

General rule - consent needed

5(1) A health care provider must not provide any health care to an adult without the adult's consent except under sections 11 to 15.

A health care provider must not seek a decision about whether to give or refuse substitute consent to health care under section 11, 14 or 15 unless he or she has made every reasonable effort to obtain a decision from the adult.

Elements of consent

6 An adult consents to health care if

(a)the consent relates to the proposed health care,
(b) the consent is given voluntarily,
(c) the consent is not obtained by fraud or misrepresentation,
(d) the adult is capable of making a decision about whether to give or refuse consent to the proposed health care,
(e) the health care provider gives the adult the information a reasonable person would require to understand the proposed health care and to make a decision, including information about

(i) the condition for which the health care is proposed,
(ii) the nature of the proposed health care,
(iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and
(iv) alternative courses of health care, and

(f) the adult has an opportunity to ask questions and receive answers about the proposed health care.

1993-48-6.

How incapability is determined

7 When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands

(a) the information given by the health care provider under section 6 (e), and
(b)that the information applies to the situation of the adult for whom the health care is proposed.

1993-48-7.

Duty to communicate in appropriate manner

8 When seeking an adult's consent to health care or deciding whether an adult is incapable of giving, refusing or revoking consent, a health care provider

(a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and
(b) may allow the adult's spouse, or any relatives or friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.

1993-48-8.

How consent is given and scope of consent

9(1) Consent to health care may be expressed orally or in writing or may be inferred from conduct.

(2) Consent to health care applies only to the specific health care that an adult has consented to.

(3) However, a health care provider may provide additional or alternative health care to an adult if

(a) the health care that was consented to is in progress,
(b) the adult is unconscious or semi-conscious, and
(c) it is medically necessary to provide the additional or alternative health care to deal with conditions not foreseen when consent was given.

(4) If an adult who consents to health care stipulates that the health care must be provided by a named health care provider, no one else my provide the health care without first obtaining the adult's consent unless the health care is in progress, or delay is likely to put the adult's life or health at risk.

1993-48-9.

Same rules apply to substitute consent

10 Sections 6, 7, 8 and 9 apply when a decision about whether to give or refuse substitute consent is sought or made under section 11, 14 or 15.

1993-48-10.

Exception - urgent or emergency health care

12(1) A health care provider may provide health care to an adult without the adult's consent if

(a) it is necessary to provide the health care without delay in order to preserve the adult's life, to prevent serious physical or mental harm or to alleviate severe pain,
(b) the adult is apparently impaired by drugs or alcohol or is unconscious or semi-conscious for any reason or is, in the health care provider's opinion, otherwise incapable of giving or refusing consent,
(c) the adult does not have a substitute decision maker, guardian or representative who is authorized to consent to the health care, is capable of doing so and is available, and
(d) where practicable, a second health care provider confirms the first health care provider's opinion about the need for the health care and the incapability.

(2) For the purpose of this section, a substitute decision maker, guardian or representative is available if it is possible for the health care provider, within a time that is reasonable in the circumstances,

(a) to determine whether the adult has a substitute decision maker, guardian or representative, and
(b) to communicate with the adult's substitute decision maker, guardian or representative.

1993-48-12.

Temporary substitute decision makers

16(1) To obtain substitute consent to provide major or minor health care to an adult, a health care provider must choose the first, in listed order, of the following who is available ad qualifies under subsection (2):

(a) the adult's spouse;
(b) the adult's child;
(c) the adult's parent;
(d) the adult's brother or sister;
(e) anyone else related by birth or adoption to the adult.

(2) To qualify to give, refuse or revoke substitute consent to health care for an adult, a person must

(a)be at least 19 years of age,
(b) have been in contact with the adult during the preceding 12 months,
(c) have no dispute with the adult,
(d) be capable of giving, refusing or revoking substitute consent,
(e) and be willing to comply with the duties in section 19.

(3) If no one listed in subsection (1) is available or qualifies under subsection (2) or if there is a dispute about who is to be chosen, the health care provider must choose a person, including a person employed in the office of the Public Guardian and Trustee, authorized by the Public Guardian and Trustee.

(4) A health care provider is not required to do more than make the effort that is reasonable in the circumstances to comply with this section.

Authority of a temporary substitute decision maker

17(1) A person chosen under section 16 has, for a period of 21 days from the date of being chosen, the authority to give or refuse substitute consent to health care for the adult.

(2) Subsection (1) applies even if the health care is for a continuous period that extends beyond the 21 day period so long as the health care begins before that period ends.

(3) [Not in force] Within the 21 day period, the person chosen under section 16 may apply to the court under the *Adult Guardianship Act* for an order appointing a substitute decision maker or guardian for the adult.

(4) [Not in force] If an application is made under the *Adult Guardianship Act*, the applicant's authority to give or refuse substitute consent under this Act extends beyond the 21 day period until a final order is made.

(5) On being told that a person chosen under section 16 wants to be relieved of the responsibility of giving or refusing consent, the health care provider may choose another person in accordance with that section to assume that responsibility for the remainder of the 21 day period.

(6) A person chosen under section 16 has the right to all the information necessary to make an informed decision under subsection (1) of this section.

(7) Anyone who has custody or control of the information referred to in subsection (6) must disclose that information to the person chosen under section 16.

(8) Subsections (6) and (7) override

(a) any claim of confidentiality or privilege other than a claim founded on solicitor client privilege, and

(b) any restriction, in an enactment or the common law, about the disclosure or confidentiality of information.

1993-48-17.

Restrictions on authority of a temporary substitute decision maker

18(1) A person chosen under section 16 does not have authority to give substitute consent to any type of health care prescribed in the regulations.

(2) A person chosen under section 16 has authority to refuse substitute consent to health care necessary to preserve life, but only if there is substantial agreement among the health care providers caring for the adult that

(a) the decision to refuse substitute consent is medically appropriate, and
(b) the person has made the decision in accordance with section 19 (1) and (2) (a).

(3) [Not in force] If any person referred to in subsection (2) does not agree on any matter referred to in subsection (2) (a) or (b), that person or the Public Trustee may apply under the *Adult Guardianship Act* for the appointment of a substitute decision maker or guardian for the adult.

1993-48-18.

Duties of a temporary substitute decision maker

19(1) A person chosen under section 16 to give or refuse substitute consent to health care for an adult must

(a) before giving or refusing substitute consent, consult, to the greatest extent possible,

(i) with the adult, and
(ii) if the person chosen under section 16 is a person authorized by the Public Guardian and Trustee, with any friend or relative of the adult who asks to assist, and

(b) comply with any instructions or wishes the adult expressed while he or she was capable.

(2) If the adult's instructions or wishes are not known, the person chosen under section 16 must decide to give or refuse consent

(a) on the basis of the adult's known beliefs and values, or
(b) in the adult's best interests, if his or her beliefs and values are not known.

(3) When deciding whether it is in the adult's best interests to give, refuse or revoke substitute consent, the person chosen under section 16 must consider

(a) the adult's current wishes,
(b) whether the adult's condition or well-being is likely to be improved by the proposed health care,
(c) whether the adult's condition or well-being is likely to improve without the proposed health

care,
(d) whether the benefit the adult is expected to obtain from the proposed health care is greater than the risk of harm, and
(e) whether a less restrictive or less intrusive form of health care would be as beneficial as the proposed health care.

1993-48-19.

Part 4 - Reviews and Appeals

Health Care and Care Facility Review Board

27(1) The minister must establish a Health Care and Care Facility Review Board, appoint its members and designate a member of the board as its chair.

(2) The chair of the board may establish one or more panels of the board and designate the chair of each panel established and a panel, if established, must include at least

(a) one health care provider,
(b) one member of the Law Society of British Columbia, and
(c) one person who is not a health care provider nor a member of the Law Society of British Columbia.

(3) If a panel is established

(a) the chair of the board may refer matters that are before the board to a panel or a matter that is before a panel to the board or another panel
(b) the panel has all the jurisdiction and may exercise and perform the powers and duties of the board with respect to matters that come before the panel,
(c) the board or 2 or more panels may proceed with separate matters at the same time, and
(d) a decision or order of the panel is a decision or order of the board.

(4) The members of the board are entitled to be reimbursed by the minister for reasonable travelling and other out of pocket expenses necessarily incurred in discharging their duties, and may be paid remuneration set by the Lieutenant Governor in Council.

1993-48-27.

Requests for review

28(1) A request may be made for a review of

[Not in force] a decision that the adult to whom health care is provided or for whom health care is proposed is incapable of giving, refusing or revoking consent to health care, [Not in force] a decision to choose a particular person under section 16 to give, refuse or revoke substitute consent to health care, a decision to give, refuse or revoke substitute consent to health care, [Not in force] a decision that an adult is incapable of rejecting a facility care proposal, [Not in force] a decision to accept or reject a facility care proposal, [Not in force] a decision to restrain an adult's freedom of movement within a care facility, or [Not in force] a decision that an adult is incapable of deciding to move out of a care facility. Any of the following may

request a review: an adult to whom health care is being provided or for whom health care is proposed; [Not in force] an adult who is living in a care facility or for whom a care facility is proposed; a spouse, relative or friend of anyone referred to in paragraph (a) or (b); the substitute decision maker, guardian or representative of anyone referred to in paragraph (a) or (b);

(d.1) a health care provider caring for the adult referred to in paragraph (a);

a prescribed advocacy organization in prescribed circumstances; the Public Guardian and Trustee. [Not in force] A request for a review made under subsection (1) (a) must be accompanied by the report of an assessment arranged under section 14 (2).

(4) [Not in force. Repealed 1999-25-15.]

(5) The request must be delivered to the board within 72 hours after the decision is made.

(6) The board must give the parties written notice of the request for a review and of the time, date and place of the hearing.

(7) The parties to a review are

the person who requested the review, the adult to whom health care is provided or for whom health care is proposed, or [Not in force] who is living in the care facility or for whom a care facility is proposed, and the person whose decision is being reviewed.

1993-48-28.

Footnotes

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[1] R.S.B.C. 1996, c. 181, as amended, ("The HCCF Act" or "The Act"), Parts 1 and 2 of which came into force as of February 28, 2000.

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[2] R.S.B.C. 1996, c. 405 (Supp.), as amended.

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[3] R.S.B.C. 1996, c. 6, as amended.

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[4] R.S.B.C. 1996, c. 349.

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[5] The term "surrogate decision maker" is used in this document to refer generally to those who give, refuse or revoke substitute consent with regard to health care. The term "substitute decision maker" refers to a particular type of surrogate decision maker who may be appointed under as yet unproclaimed provisions of the Adult Guardianship Act, R.S.B.C. 1996, c. 6, and is used in this document only in that sense. The giving, refusing or revoking of substitute consent to health care is sometimes referred to herein as "substitute decision making."

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[6] (1914) 211 N.Y.R. 125, at 129-30.

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[7] (1980) 112 D.L.R. (3d) 67.

[8] (1980) 114 D.L.R. (3d) 1.

[9] S. 3(1)(a).

[10] S. 3(2).

[11] S. 5(b).

[12] S. 5(e).

[13] The text of relevant sections of the Act are set out in Appendix II.

[14] The discrepancy between, for example, s. 17(1), which refers to giving or refusing consent, and s. 16(2), which refers to giving, refusing, or revoking consent, is discussed below under Issue II.

[15] As indicated in note 5, in this document, "substitute decision making with regard to health care" should be taken to denote, following the provisions of the HCCF, the giving, refusing or revoking of substitute consent to health care. The scope of such decision making is discussed under Issue IV.

[16] See Issue IIIa below.

[17] See *Representation Agreement Act*, ss. 16(2)-(4) and (7), and *Adult Guardianship Act* s. 29.

[18] S. 19(1).

[19] S. 16(2)(b).

[20] S. 29(1)(b), as yet unproclaimed.

[21] This problem is discussed as Issue II above, and in more detail below.

[22] As yet unproclaimed.

[23] Albeit subject to the limits, discussed above, as to criteria that may be relied upon, and the further restriction of "medical appropriateness" for TSDMs, to be discussed immediately below.

[24] Emphasis added.

[25] S. 6(e)(i) refers to an obligation to provide information about "the condition for which the health care is proposed."

[26] Emphasis added.

[27] [1998] 4 W.W.R. 29.

[28] At p. 32.

[29] (1998) 167 D.L.R. (4th) 359.

[30] (1997) 152 D.L.R. (4th) 724.

[31] R.S.B.C. 1996, c. 349.

[32] See *Representation Agreement Act* s. 30, especially s. 30(1)(c) and (i).

[33] See Adult Guardianship Act ss. 36 and 37.

[34] See *Representation Agreement Act*, s. 32, and *Adult Guardianship Act*, s. 38(3) and (4).

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