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HEALTH CARE CONSENT AND ADVANCE CARE PLANNING IN ONTARIO

Legal Capacity, Decision-Making and Guardianship January 2014

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EXECUTIVE SUMMARY

This Paper focuses on the interrelationship between health care consent and advance care planning under Ontario law, and on related misconceptions of health practitioners and health care organizations.

At common law and under Ontario legislation, informed consent is required before a health practitioner can provide treatment to a patient. Importantly, where a patient is incapable, the requirement to obtain informed consent is not abrogated, but instead the informed consent is obtained from communications with substitute decision-makers (SDMs).

There has been an increasing emphasis in Ontario, and other common law jurisdictions, on encouraging patients to pre-plan for future treatments that may become necessary if and when the patient becomes incapable. This often means that health practitioners will solicit patients' wishes, values and beliefs relevant to future care decisions, and then record such wishes, values and beliefs in the patient's health record. Unfortunately, at the time of these future care discussions, health practitioners and patients do not always turn their minds to how these wishes, values and beliefs will affect future health care decision-making. Similarly, health practitioners do not always provide patients with sufficient information in order to express informed and robust wishes about future care. In Part 1 of this Paper, we explain our concerns arising from this trend.

As set out in Part II of this Paper, the increasing emphasis on uninformed future care wishes creates a tension between two sides of the principle of patient

autonomy. On the one hand, patients have the right to give informed consent to treatment: health care consent will only be legally valid if the health practitioner discusses the nature, risks, benefits, side effects of, and alternatives to, a particular treatment. On the other hand, patients have a right to express wishes regarding the care they may someday receive when they are incapable, and to have those wishes complied with in certain circumstances. Where a patient has expressed an uninformed wish about future care, these two sides of patient autonomy come into tension. In Ontario, this tension has been resolved by requiring that SDMs give informed consent on behalf of incapable patients. In giving or refusing informed consent, SDMs are mandated to follow the patient's applicable prior capable wishes. Not all jurisdictions have balanced these competing interests in the same manner as Ontario.

In Part III of this Paper, we provide an in-depth summary of the law of Ontario on health care consent, capacity and substitute decision-making. This Part concludes that, under Ontario legislation, with the narrow exception of treatment in emergencies, informed consent must always be obtained from a patient (or if incapable, his/her SDM) before treatment is administered). The patient (or SDM) can only lawfully give informed consent to treatments that relate to the patient's current health condition. Where a patient is incapable, an SDM is required to determine whether the patient has expressed applicable prior capable wishes (which must be followed by the SDM), or otherwise has expressed other

wishes, values, and beliefs (which must be considered), in giving or refusing informed consent.

In Part IV, we explore how advance planning fits into Ontario's laws on health care consent, and summarize how different examples of advance care planning have been interpreted by Ontario Courts and administrative tribunals. We also recognize that advance care planning encompasses a myriad of statements and documents. Under Ontario law, all wishes, values and beliefs must be analyzed to determine whether they are sufficiently specific to be "wishes" or are merely the patient's "values and beliefs". If "wishes", the incapable patient's current clinical picture must be carefully considered by the SDM to determine if these "wishes" are "applicable to the circumstances" (and must be followed) or are merely "with respect to the treatment" (and must be considered along with the patient's values and beliefs). The SDM is the primary interpreter of the incapable patient's wishes, values and beliefs. However, SDMs cannot themselves advance care plan on behalf of patients. Importantly, except in emergencies, advance care planning can only be given effect through informed consent to treatment.

In Part V, we examine the relationship between health care consent and advance care planning in several extra-provincial and international jurisdictions. We conclude that the relationship between health care consent and advance care planning in Ontario law is somewhat unique. Unlike other jurisdictions, Ontario law:

- (a) does not allow prior capable wishes to be given effect without interpretation by an SDM (except in emergencies),
- (b) does not prioritize formalized 'advance directives' over informally expressed wishes, values and beliefs, and,
- (c) places a great deal of emphasis on contextualizing health care decision-making in the patient's current health condition.

We express our preference for Ontario law over the other statutory models examined - because Ontario's legislation appropriately balances informed consent to treatment with the applicability of prior statements made by the patient.

In Part VI, we describe the operationalization of the law of health care consent and advance care planning in Ontario. In this Part, we critique some of the key educational and policy documents governing health practitioners, review standardized forms and systems for recording and implementing health care consent and advance care planning, and describe the results of our survey of health care organizations' documents and our focus groups with important stakeholders.

In Part VII, we identify concerns arising from our research into the operationalization of the law of health care consent and advance care planning in Part VI. We conclude that policies, forms, and health practitioners do not place enough emphasis on informed consent to treatment, and instead focus on the solicitation and recording of patient wishes, values and beliefs. In a similar vein, we note a common misconception in Ontario that formalized 'advance directives' can be acted upon directly by health practitioners where the patient is incapable.

In fact, the law in Ontario is that all patient wishes regarding future care must be interpreted by an SDM as part of the process of giving informed consent on behalf of an incapable patient (except in emergencies). Similarly, we note that some health care organizations believe that health practitioners should be pre-screening the treatments proposed to SDMs on the basis of the incapable patient's prior expressed wishes, values and beliefs. In the authors' view, this has the potential to usurp the statutory role of the SDM as the interpreter of the patient's wishes in giving or refusing consent.

We also identify a concern that many health care organizations' advance care planning forms incorrectly provide that they can be completed by SDMs – when under Ontario law SDMs cannot advance care plan on behalf of incapable patients. Lastly, we note our concern that health practitioners in Ontario are uncritically relying on advance care planning documents and research from other jurisdiction, which may not be applicable in Ontario.

In Part VIII, we make recommendations for addressing the issues identified in Part VII. The overarching goal of these recommendations is to encourage health practitioners and health care organizations to emphasize contextualized patient decision-making over rote recording and application of wishes, values and beliefs:

- **Give Priority to Consent to Treatment:** Institutional and regulatory policies and practices should encourage health practitioners to seek consent to a plan of treatment to the greatest extent possible before soliciting wishes, values and beliefs. While a process that emphasizes the importance of knowing the general wishes of a patient is important, more

- education is needed about closing the loop by seeking informed consent to a proposed treatment, rather than relying on wishes alone;
- **Use a clarified Advance Care Planning Model addressing its relationship with Health Care Consent:** We suggest closing the loop on how health practitioners think about advance care planning. The current practice in Ontario has advance care planning front-loaded to the point where the 'back-end' consideration of patient wishes, values, and beliefs appears to be secondary to their 'front-end' expression. More emphasis should be placed on advance care planning at the 'back-end': i.e., to the contextualized informed consents or refusals of SDMs (if the patient is incapable). We recommend conceptualizing health care consent with advance care planning as a three part process involving:
 - (1) Identifying the future SDM by the capable patient;
 - (2) Recording wishes, values, and beliefs expressed by the patient when capable; and,
 - (3) Obtaining health care consent from the patient (or SDM if the patient is incapable), even if there is an advance care plan.
 - **Use the Terminology in the Ontario *Health Care Consent Act*:** Health practitioners, and institutional policies and forms should use the language expressed in the *Health Care Consent Act* when seeking health care consent and engaging in advance care planning. The use of language such as 'directions,' 'decisions' and 'living wills' should be discouraged in Ontario. Similarly, the term 'Advance Directive' should not be used in Ontario on health care forms, institutional policies, or in discussions with patients. These terms would appear to be transplanted from other jurisdictions where, for example, an advance directive or a living will are specific documents that 'direct' treating health practitioners. The use of these terms could lead patients, SDMs and health practitioners to misunderstand Ontario's legislative scheme for giving and refusing informed consent; and,
 - **Revise the *Health Care Consent Act* to make advising the SDM of his/her rights and obligations part of informed consent:** With knowledge of their role to interpret and apply prior capable wishes, and to make decisions in the patient's best interests, active SDMs could help health practitioners ensure that advance care planning tools and forms are used appropriately, and that informed consent is obtained. From a practical perspective, the best way to ensure that SDMs obtain the

information they need to make decisions on behalf of incapable patients is for health practitioners to provide this information to them. We recommend that, in addition to health practitioners' current statutory obligation to obtain informed consent, health practitioners also be statutorily obliged to inform SDMs of their role. Where health practitioners fail to comply with this requirement, a consent obtained from an SDM will not be lawfully obtained, with all of the same legal consequences as currently exist.

To address the misconceptions we have identified, we suggest a comprehensive education program for all health practitioners, with specific emphasis on those practicing in hospitals, long-term care homes, and retirement homes (as well as community agencies), providing training on the Ontario law of informed consent to treatment and its relationship to advance care planning. This educational program should be tied to funding of health care organizations. We also provide examples of how this educational program could be mandated legislatively.

I. INTRODUCTION

A. Background to this Research Project

At common law and under Ontario legislation, informed consent is required before a health practitioner can provide treatment to a patient.¹² This is the lens which focuses and guides the analysis of many health law problems encountered by the authors in daily legal practice. While there are exceptions to the requirement to obtain informed consent, these are narrow and time-limited.

Where a patient is incapable of giving or refusing informed consent to treatment, the common law has historically provided incomplete guidance to health practitioners on when, and in what circumstances, treatment can be provided. In Ontario, this issue has been legislatively addressed through the *Health Care Consent Act, 1996*³ [the “HCCA”] and its predecessor legislation. The HCCA sets out an overarching requirement to obtain informed consent to treatment (except in emergencies), and also provides for a hierarchy of substitute decision-makers (“SDMs”) who may give or refuse consent in place of the patient where that patient is incapable.

Importantly, where a patient is incapable, the requirement to obtain informed consent is not abrogated, but instead the informed consent is obtained from communications with SDMs. In this way, consent in Ontario must always come from contextualized communications with a person (either the patient or the patient’s SDM) and can never come solely from a document.

While health practitioners are required to obtain informed consent from patients before providing a proposed treatment (except in an emergency), many health care organizations have developed policies and practices encouraging or requiring patients (or if incapable, their SDMs) to articulate the types of health care they might want in the future. In many cases, this occurs upon admission to a health care organization or service. On the one hand, this pre-planning is a welcome development (because patients are turning their minds to what they would want in the future) but it is also potentially problematic: discussions around future health care typically occur in a factual vacuum, without specific reference to the patient's current health condition or prognosis. This creates a risk that patients are expressing uninformed and arguably low-quality wishes (e.g. wishes that are less likely to reflect the decision the patient would make if capable in the future and fully informed of the risks and benefits of treatment). Often, these discussions about future health care are imposed by health care organizations, prematurely and subject to arbitrary timelines. This emphasis on pre-planning has also extended to other settings where health services are provided, such as long-term care homes, retirement homes, and home care.

Patients are often required to participate in this "advance care planning" by giving what are sometimes referred to as "advance directives" about specific treatments they will accept or refuse in future. "Advance care planning" is a generic term used across many Canadian and international jurisdictions to describe the process of planning by an individual for a time when he or she no

longer has the mental capacity to make health care decisions. Advance care planning is comprised of two elements:

(1) Identification of the individual who will make decisions for the patient in the event the patient becomes incapable (sometimes referred to as a “Proxy Directive,” as the patient is designating their proxy decision-maker). The Proxy is referred to as an SDM in the HCCA; and,

(2) Expression of wishes, values, and beliefs about future health care decisions to be made in the event the patient becomes incapable (sometimes referred to as the “Instructional Directive,” as the patient is giving instructions about future care). In the HCCA, these instructions are referred to as “wishes”.

This research paper on health care consent and advance care planning in Ontario (the “Paper”) focuses on persistent misconceptions around the use of instructional directives in Ontario, rather than the designation of proxy decision-makers. This is largely because in Ontario there is a hierarchy of SDMs already established under section 20 of the *HCCA*, which sets out the default SDM(s) of a patient, unless he or she makes a choice to deviate from the ranking (the exception is where a person other than the patient applies to become the patient’s representative, which will be discussed further below).

In many settings, forms or documents (such as “level-of-care” forms or other advance directive forms) are used to record instructional directives. In Ontario, with the narrow exception of emergency treatment, health practitioners can only give effect to prior expressions of wishes, values and beliefs through informed consent to treatment by an SDM.

“Advance directive” is a generic term used in Ontario to refer to specific communications from a patient containing his/her wishes regarding health care

choices in the future. However, in many other jurisdictions this phrase refers instead to a formal document providing directions specifically to a health practitioner. The term “advance directive” is also sometimes used beyond the expression of wishes, values, and beliefs (instructional directives) to refer to the designation of an SDM (a proxy directive).

The terms “advance care planning” and “advance directive” do not appear in the *HCCA*, nor in the *Substitute Decisions Act, 1992* (the “*SDA*”): collectively, the Ontario statutes governing health care consent and substitute decision-making. With regard to the designation of an SDM, the *SDA* refers only to the designation of an attorney pursuant to a power of attorney for personal care. With regard to future health care instructions, the *HCCA* refers only to the patient’s “wishes”, “values” and “beliefs”. The use of the language of wishes, values and beliefs reflects the fact that an individual may not always have all of the necessary information required to give an informed consent when speaking about future health care. Wishes, values and beliefs will eventually guide that individual’s SDM when a treatment is proposed and substitute consent is required. An SDM must act in accordance with the patient’s applicable prior capable wishes and, if none were expressed, must consider the patient’s other wishes, values and beliefs in deciding what is in the patient’s best interest (as that term is defined in the *HCCA*).

Importantly, wishes, values and beliefs expressed by an SDM have no legal effect, unless such wishes were expressed, or such values and beliefs were

held, *by the now incapable patient*. In short, no legal effect is given to *new* wishes, values, and beliefs where they are expressed by an SDM. Under Ontario legislation, the SDM's role is solely to give or refuse consent to treatment and to recount the patient's wishes, values and beliefs to health practitioners. The SDM may not make new wishes on behalf of the incapable patient. Only the patient can express wishes, values and beliefs to guide their own future care. This point cannot be emphasized enough, given that SDMs do occasionally try to assert new wishes on behalf of incapable patients.

While legal effect is not given to *new* wishes, values, and beliefs expressed by the SDM, SDMs can lawfully give informed consent to a plan of treatment governing future care to be provided to the patient. This is permitted only if this consent is limited to care related to the patient's current health condition. This is one of the most significant (and potentially least understood) issue in advance care planning in Ontario: only a capable patient may make wishes governing future treatment, whereas either a capable patient or if incapable, an SDM, may provide an informed consent to a plan of treatment (including its withholding or withdrawal), tied to the patient's current health condition. This will be discussed in detail below.

In the authors' view, the Ontario model of decision-making for incapable patients provides an appropriate balance between the right of patients to direct their own health care and the risk that patients may be inadvertently trapped by inapplicable and categorical wishes expressed while capable. Prior capable

wishes may not reflect the decision the patient would make if capable today. When applied properly, the law in Ontario ensures an opportunity for patients, while capable, to express wishes about their future care and treatment. It also enables SDMs to interpret and apply the patient's wishes when the SDM is called upon to give or refuse informed consent for an incapable patient. Importantly, we believe the law in Ontario is also good for health practitioners, as it allows health practitioners to take direction from an SDM rather than be required to make decisions for patients. Except in emergencies, health practitioners are relieved from deciding the value of their services to patients, and can rely on the clear hierarchy of SDMs set out in the *HCCA*.

Unfortunately, there are persistent misconceptions around the use of instructional directives in Ontario. Some health practitioners in Ontario mistakenly believe that written advance directives are equivalent to informed consent. For example, if an advance directive is included with the patient's record of personal health information (such as the hospital chart), some health practitioners erroneously believe they can bypass patients or their SDMs when a treatment decision is required. They may incorrectly treat a recorded wish as sufficient and binding – regardless of whether the patient is capable or incapable of giving informed consent with respect to the proposed treatment. Even if health practitioners seek informed consent where a wish has been expressed, the health practitioner may pre-screen possible treatment options proposed to the patient or the SDM based on an interpretation of the patient's wishes.

As noted above, in some other jurisdictions, an advance directive is a direction specifically to the treating health practitioner, who does not then need to obtain consent from an SDM before providing treatment. The difficulty with this model, which was not adopted in Ontario, is that it gives sole authority to health practitioners to determine the applicability of a patient's prior capable wishes. This often means that health practitioners with only passing contact with a patient are given authority to decide whether to administer the treatments they are proposing, with only a sparsely worded written directive as their guide.

The authors do not recommend following other jurisdictions' models for advance care planning. Such models generally give a great deal of authority to health practitioners to make end-of-life decisions for patients - interpreting patient wishes, values and beliefs. These models also tend to de-emphasize informed consent to treatment and contextualized decision-making, and instead, replace them with rote recording and implementation of paper forms. Both of these facets may increase the risk of inauthentic decision-making.

In Ontario, informed consent is a process that requires communication, almost always oral, between a health practitioner and the patient or SDM. While consent can and should be recorded by the health practitioner in writing once obtained, it must always come from a contextualized discussion with the patient or SDM (if the patient is incapable) about patient's health condition and treatment options (and not from a form).

Misinterpretations about health care consent and advance care planning may also have a disproportionate impact on patients and SDMs who are more vulnerable due to age, disability, cultural background and/or health literacy, and who may, as a result, be excluded from appropriate health care decision-making contrary to the law.

In an effort to influence both law reform in Ontario and the best practices of health care organizations and health practitioners, this Paper will explore the standards, information and supports that are statutorily mandated or voluntarily available to those creating, exercising and applying health care consent and advance care planning tools. We will also analyze the legislative schemes in select jurisdictions to contrast what is in place in Ontario, and how the laws of these jurisdictions may contribute to persistent misunderstandings of Ontario law.

B. Structure of this Paper

This Paper begins with a conceptual primer on the principle of patient autonomy followed by a factual primer on advance care planning. It then provides a comprehensive explanation of Ontario's health care consent and substitute decision-making laws. This is followed by a discussion of how advance care planning and advance directives fit within Ontario law. We then examine the laws of other provinces and countries.

Following this review of the law, we examine how health care consent and advance care planning are operationalized in Ontario. This is done through a review of policies, procedures and the results of our focus groups with

stakeholders, including representatives of seniors' organizations, lawyers practicing in this area and health practitioners. Finally, we summarize the issues we have identified in Ontario and make recommendations for possible reform and/or education.

C. Advocacy Centre for the Elderly (ACE)

ACE is a specialty community legal clinic that was established to provide a range of legal services to low income seniors in Ontario. These legal services include individual and group client advice and representation, public legal education, community development and law reform activities. ACE has been operating since 1984 and it is the first and oldest legal clinic in Canada with a specific mandate and expertise in legal issues of the older population. A significant portion of the practice at ACE is focused on health law issues related to patient's rights, health consent, and substitute decision-making. Over the years, ACE lawyers have been directly involved in many of the major initiatives in Ontario on these issues including the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons, the Ontario Strategy for Alzheimer Disease and Related Dementias, Initiatives #2 and #7 on Physician Training, and Advance Directives on Care Choices and currently the Ontario Medical Association President's Advisory Panel on End-of-Life care.

Judith Wahl was appointed by the Ontario Attorney General to act as the Chair of the Interim Advisory Committee for the Implementation of the *Substitute Decisions Act*, and was a primary writer of the content of the health professionals'

training manual for the Alzheimer's Physicians' Training which focused on health care consent and advance care planning . She has been a presenter and teacher at numerous educational forums on consent and advance care planning for seniors and their families, as well as for health professionals.

Brendan Gray was called to the bar in 2010 after articling as a judicial law clerk for the judges of the Ontario Superior Court of Justice in Toronto. Following his call to the bar, Brendan practiced in the private bar with a particular focus on health law at a litigation firm in Toronto, and joined ACE in 2013. Brendan has represented clients in health law related proceedings at all levels of Ontario Courts.

D. Dykeman Dewhirst O'Brien LLP (DDO)

DDO is a boutique health law firm located in Toronto, serving primarily institutional clients such as public hospitals, long-term care homes, community mental health and addictions agencies, family health teams and community health centres. A significant portion of the advice DDO lawyers provide relates to consent, capacity and substitute decision-making, advance care planning, end-of-life, and difficult situations involving patients/residents and families. Mary Jane Dykeman was previously in-house counsel to the Psychiatric Patient Advocate Office, as well as to two Toronto teaching hospitals (one with a major long-term care facility). She sits on the board of the Alzheimer Society of Toronto and chairs the Board of the Anne Johnston Health Station, a community health centre serving seniors, the barrier-free (clients with mobility issues) and youth.

E. Methodology

The methodology for preparing this Paper was comprised of three main parts: (1) a literature review; (2) a survey of institutional policies and practices; and (3) conducting focus groups and meetings with stakeholders.

1. Literature Review

We conducted a comprehensive literature review of issues surrounding health care consent and advance care planning, including:

- Provincial and international legislation;
- Policies and practices;
- Case law;
- Academic articles;
- Advance Care Planning tools, forms and systems; and,
- Web-based materials.

In addition to reviewing the laws and policies of Ontario, we examined legislation in four other Canadian provinces: British Columbia, Alberta, Nova Scotia and Saskatchewan. Outside Canada, we examined legislation in Queensland (Australia), England, Hawaii (USA), Oregon (USA), and Texas (USA). We chose these jurisdictions for a variety of reasons, including: language (these countries speak and write in English, and their statutes are readily available in English); similar legal systems; varying size (in terms of both geography and population); and noteworthy laws and/or approaches to health care environments.

The purpose of the comparative review was to analyze different legal models to explore how those models differ from the laws of Ontario, and how those models may contribute to persistent misunderstandings around Ontario's laws on health care consent and advance care planning. Due to the time constraints of the project, our analysis was not exhaustive. There may also be gaps between what is legislatively required and what happens in practice in other jurisdictions, as is the acknowledged experience in Ontario.

2. Survey of Institutional Policies and Practices

We conducted a survey of institutional policies and advance care planning documents to critique how Ontario's laws on consent and capacity are applied throughout the province. We requested that public hospitals and long-term care homes provide copies of:

- (a) excerpts from training materials, guides, and/or operational manuals that relate to consent to treatment, advance care planning, and/or substitute decision making;
- (b) documents made available to patients and/or substitute decision makers relating to consent to treatment, advance care planning, and/or substitute decision-making (e.g., information pamphlets given to SDMs); and,
- (c) standardized forms, templates, tools, and questionnaires used by health professionals to record consent or advance care plans (e.g. level of care, do not resuscitate ("DNR"), and consent forms).

We were fortunate to have the assistance of numerous health sector organizations and governmental regulators in facilitating our request for policies and forms from long-term care homes and hospitals.⁴

In collecting documents from long-term care homes and hospitals, we undertook to not identify any particular health care organization in our final report, nor to disclose the contents of documents provided to us unless information identifying each participating organization had been removed. This is in keeping with the overall goal of this Paper to positively influence law reform and best practices, rather than to critique or publicize how particular health care organizations operationalize consent, capacity and substitute decision-making.

In total, we received documents from thirteen health care organizations from geographically diverse regions of Ontario. We received documents from hospitals, private long-term care homes, municipal long-term care homes and other institutions.

3. Meetings with Stakeholders

We met with a range of stakeholders to obtain their understanding of Ontario's laws on consent, capacity, substitute decision-making and advance care planning, and on how health practitioners interpret and apply these laws in daily practice. Our primary goal was to speak with health practitioners, as they have the direct responsibility for obtaining informed consent to treatment and giving effect to advance care planning. We also had the opportunity to hear the views of focus groups comprised of seniors and lawyers, respectively. These focus groups provided anecdotal evidence but did not attempt to rise to the level of generalizable conclusions.

(a) Health Practitioners Focus Groups

Consultations and meetings with health practitioners for this project took place primarily between October and late November 2013. The breakdown of health practitioners at each meeting varied. At some meetings, the participants were primarily physicians. At other meetings, the participants were a broader cross-section of health professionals. Some of our consultations for this report were incorporated into scheduled educational sessions for health practitioners given by the authors. These educational sessions took place in Sarnia, Chatham, Windsor, Sudbury, and Toronto. Other consultations occurred during separately scheduled meetings organized specifically for this research project in Sarnia, Chatham, and Windsor (with the assistance of project staff at the Erie St Clair Local Health Integration Network (LHIN)) and in North Bay (organized with the help of a palliative care project manager at the North East LHIN). Below, we provide a list of the location of each presentation/consultation and the approximate number of participants:

- **Toronto:** Presented at four sessions during the Ontario Long-Term Care Physicians (OLTCP) Annual Meeting. These sessions occurred on October 26 and 27, 2013 with approximately 40 participants at each session.
- **North Bay:** Presented at a meeting of palliative care practitioners (various health practitioners) organized by the North East Regional Hospice Palliative Care Coordinator, North East LHIN. This meeting occurred on November 5, 2013 with approximately 20 participants.
- **Sudbury:** Presented at a meeting at the Northeast CCAC organized by the North East Regional Hospice Palliative Care Coordinator, North East LHIN. This meeting occurred on November 7, 2013 with approximately 60 participants.

- **Sarnia, Chatham and Windsor:** Presented at meetings organized by the Erie-St Clair LHIN. There were two sessions at each site on October 7-9, 2013 to approximately 265 total participants.

Neither the sampling of health practitioners, nor the phrasing of questions and follow-up questions to participants were intended to reach the level of a formalized scientific study. Instead, these were viewed as more informal stakeholder consultations.

(b) Seniors Focus Group

The authors conducted a focus group with long-term care residents and representatives of seniors' organizations to obtain stakeholder input on the application of health care consent and advance care planning in the real world. While again these focus groups did not meet the rigours of scientific sampling, they were nonetheless invaluable to the authors in providing insight into some of the concerns seniors have with the process of health care decision-making.

ACE has extensive connections with seniors organizations throughout the province of Ontario (and nationally), and the authors sent invitations to almost all of these organizations requesting their participation in this research project. Groups were selected for invitation based on their involvement with health care matters and long-term care homes. Our seniors' stakeholder focus group was comprised of eight individual representatives of the following organizations:

- Canadian Pensioners Concerned;

- Family Councils' Program (an organization that facilitates family councils in long-term care homes);
- Ontario Society (Coalition) of Senior Citizens' Organizations (OCSCO);
- Ontario Association of Residents' Councils (an organization that supports Residents' Councils in long-term care homes); and,
- the Canadian Association of Retired Persons (CARP).

Almost all of these representatives were seniors.

(c) Lawyers Focus Group

The authors conducted a focus group and other informal consultations with lawyers whose legal practices focus on elder law and health care consent. The purpose of these focus groups was to discuss the common practices of health practitioners in obtaining and acting upon informed consent and advance care planning that may not strictly comply with Ontario law. We were fortunate to discuss these issues with both prominent 'patient-side' and 'hospital-side' lawyers to understand their experiences, and to gain their insights into some of the commentary that grounds this Paper.

II. PRIMER

This section provides a primer on the principle of patient autonomy and how it relates to the issues raised in the Paper, then gives some real world examples of advance care planning. Our goal in this section is to explain some of the issues, interests and concerns underpinning the law in Ontario, and to provide context for how health care consent and advance care planning relate in practice.

We have also prepared a glossary of key terms, which can be found at the end of this Paper.

A. Balancing both sides of patient autonomy: informed consent and future care wishes

At a high level, Ontario's legislative scheme governing health care consent and substitute decision-making focuses on balancing the principle of patient autonomy with the need to protect incapable patients.⁵

The genesis of both the *SDA* and the *HCCA* can be traced back to the draft legislation prepared by the Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons chaired by Stephen V. Fram, Q.C. The final report of this committee (the "Fram Report") was released in 1988. The Fram Report noted the conflict between patient autonomy and substitute decision-making, and recommended a model of least restrictive substitute decision-making for incapable adults.⁶ The Fram Report also noted a concern that unfettered resort to substitute decision-making would be paternalistic.⁷

Much has been written on the balance between individual self-determination and substitute decision-making. This balance is *not* the focus of this Paper. Instead, this Paper focuses squarely on the principle of patient autonomy, and on how the two sides of this principle occasionally come into tension.

Patient autonomy is, broadly speaking, the right of individuals to make decisions about their own bodies. As the Fram Report noted, “The traditional democratic concept of liberty involves letting people live as they choose or wish, without interference, so long as they do not break the law or endanger others.”⁸

Courts have held that patient autonomy entails a right to be informed of the risks and benefits of treatment before lawful consent can be given. This is referred to as the doctrine of informed consent,⁹ and is fundamentally founded on the idea that capable patients should be given relevant information to make choices about their own well-being. However, patients also have a right to express wishes about the health care they will receive in the future if they become incapable, and to have those wishes complied with in certain circumstances.¹⁰ This aspect of patient autonomy entails a right to pre-plan for future health care, and a limited right to have such plans followed.¹¹

Tensions may arise where a patient has expressed a relatively uninformed wish about future health care. For example, a patient may express a wish to receive a particular end-of-life treatment. This wish may be expressed in a factual vacuum, well prior to a relevant diagnosis, and without being given any

information about this treatment from a health practitioner (as would be required by law if informed consent were being sought). When a health practitioner is later informed of such a wish having been made at a time prior to the patient's current incapacity, and the health practitioner is now proposing the particular treatment, what is he/she to do? On one hand, the health practitioner has an obligation to obtain informed consent to treatment – which can no longer be obtained from the patient because they are incapable. On the other hand, patients have a limited right to direct their future care and the physician may be under an obligation to comply with the prior expressed wish.

The common law of Ontario has never provided complete guidance on resolving this tension. The Fram Report did not address changes to the law of informed consent, but instead assumed that the common law of informed consent would continue to apply and recommended transferring the existing requirement to give informed consent from the incapable patient to the SDM.¹² However, the Fram Report also recommended that SDMs be required to make authentic decisions and follow the “intentions” of the incapable patient.¹³ Unfortunately, no guidance was provided in the Fram Report on how to address potential tensions between the principle that consent must be informed and the obligation on the SDM to follow the “intentions” of the patient (although mechanisms exist in the *HCCA* to address these tensions, discussed below).

The Fram Report's recommendation to transfer decision-making authority to an SDM where the patient is incapable was incorporated in the *HCCA*, and its

predecessor legislation. Under the *HCCA*, the SDM's role is to give or refuse informed consent on behalf of the incapable patient, and while doing so give effect to the patient's prior capable wishes. The SDM's role is to connect informed consent to treatment with the patient's future care wishes: informed consent is still obtained, but in giving or refusing consent the SDM must determine whether the patient's prior expressed wishes are applicable. This is how Ontario legislative scheme balances the patient's right to direct future care with the requirement of informed consent.

Not all jurisdictions have reached the same conclusion as Ontario on how to balance informed consent with the limited right to direct future care. British Columbia chose to legislatively remove the obligation to obtain informed consent where a health practitioner is presented with patient instructions about future care in an advance directive. Thus in B.C. no balancing is required, no tension arises, and the health practitioner may simply provide or withhold the treatment regardless of whether the advance directive was informed. The health practitioner is not required to obtain a separate informed consent from an SDM.

Readers of this paper should keep this tension, and Ontario's legislative solution, in mind. Our attempt to find the correct balance between the right of capable patients to direct their future health care, and the right of capable adults to make informed choices, weaves together many of the divergent discussions and critiques presented in this Paper.

We should note that, while advance care planning is conceptually grounded in patient autonomy, current practices in Ontario do not always further this principle. Where a patient expresses wishes about future care without being informed of useful clinical information, and is not given the opportunity to revisit such wishes when the patient's health condition changes, it is difficult to see how the principle of patient autonomy is being advanced. More emphasis on obtaining informed consent to a plan of treatment would mitigate this concern somewhat, as discussed below.

B. What kind of future care wishes should be solicited?

Closely related to the tension between informed consent and advance directives is the issue of what types of wishes about health care should be solicited from patients. This is a practical question addressing how best to connect treatment decisions with a patient's wishes, values and beliefs, and asks what will be most useful and informative to:

- (a) SDMs in deciding whether to give or refuse informed consent to treatment on behalf of incapable patients; and,
- (b) health practitioners in deciding whether to provide treatment to incapable patients in emergencies.

Most importantly, this is a question regarding what types of health care wishes will engender the most authentic decision-making possible. 'Authentic' refers to how closely a decision of an SDM (or health practitioner in an emergency) reflects the decision the patient would have made if capable.

We acknowledge that this is largely a question for health care researchers to resolve with the benefit of evidence-based research. Such research is beyond the scope of this Paper. However, as is discussed in this Paper, we do have concerns about the types of wishes that are being solicited from patients in Ontario.

Some of the documents reviewed in preparing this Paper appear to encourage low-quality and uninformed, yet very specific, expressions of prior capable wishes. For example, they encourage the general public to express absolute wishes about dialysis, mechanical ventilation, and cardio-pulmonary resuscitation (“CPR”). They attempt to collect these wishes in the abstract, without contextualizing them within the actual health condition (and likely future health condition) of the patient. This raises concerns that SDMs either will be, or will believe themselves to be, bound to make a decision in accordance with a relatively uninformed wish.

Some of the definitions of standard end-of-life treatments provided to patients in the documents we have reviewed, while not entirely inaccurate, are potentially inadequate. For example, in order to express a useful wish to receive or reject a feeding tube, a patient should be aware that this would involve the placement of a tube in the nose or abdomen. Similarly, it is difficult to imagine that a patient could express a robust wish about CPR without recognizing that chest compressions may result in numerous broken ribs. Yet, some of the documents we reviewed ask individual patients to give these specific wishes

absent this knowledge, leaving a significant information gap that health practitioners may or may not adequately fill in discussions with the patient.

The prevalence of advance care planning documents containing specific yet limited information risks encouraging low-quality expressions of future care wishes by patients. In the authors' view, it would be preferable to solicit values-based and less treatment-specific wishes to be interpreted by SDMs, rather than individual wishes about each treatment option.

We recognize that there are circumstances where categorical wishes about particular treatments will authentically reflect the decision the patient would make if capable. For example, some religious groups, such as Jehovah's Witnesses, reject human blood products regardless of the particular circumstances. However, our concern is that categorical wishes are being requested from patients whose decisions, if capable, in the future when treatment is proposed would be more flexible (meaning that patients' wishes may shift depending on the particular circumstances and the information provided by health practitioners in the future).

C. Typical advance care planning wishes

The spectrum of potentially expressed wishes about future health care is obviously very broad. Patient wishes potentially touch on almost every treatment and environment in which health care decisions are made. For the benefit of the reader, we wanted to provide some common real world examples of the types of wishes about future care that are solicited from patients by health practitioners.

Perhaps the most common, and most publically known, type of advance care planning is a wish to not be resuscitated in the event that the patient experiences a respiratory or cardiac arrest. This is commonly shortened to a Do-Not-Resuscitate (DNR) instruction. Resuscitation will generally involve the use of CPR. A prominent educational program for future physicians contains the following suggested description of CPR for use with patients in advance care planning conversations:

If your heart was to stop, you would die. A medical team or emergency paramedic team would use electric shocks to restart your heart. Even with CPR, unfortunately, the blood flow to your body is not as good as if your heart was still beating. The longer it takes to restart your heart, the more damage will occur. The sicker you are before, the less likely they are to be able to restart your heart at all.

The biggest thing to worry about is damage to your brain. If your heart cannot be restarted quickly, brain damage will occur. This brain damage can be mild, yet it is often significant and can range from loss of memory to being permanently unconscious and chronically dependent on others to help with day-to-day activities.

Within minutes of starting CPR, to increase chances of success, a tube would be put through your mouth into your windpipe to breathe for you since you would not be breathing. This is not an easy procedure and sometimes it is not successful. If your heart starts beating again, you will need to be on life support afterwards. How long you would be on life support is not clear.¹⁴

In the experience of the authors, discussions about whether the patient wishes to be resuscitated are usually solicited by health practitioners on, or shortly after, admission to any health care organization – such as a hospital or long-term care home. Unfortunately, these resuscitation discussions do not always involve transmission of the above detailed information on CPR.

Another common future care wish solicited from patients, particularly elderly long-term care home residents, relates to the “level-of-care” the resident wishes to receive. Such “level-of-care” discussions usually ask a patient or resident to select between three or four pre-selected categories of health care interventions. An example of a level-of-care form, obtained through our survey of institutional policies, provides the following options and explanations:

ADVANCE DIRECTIVES

Level One – Supportive/Comfort Care

This includes, but is not limited to, the provision of measures available within the resources of the facility such as:

- Relief of pain;
- Oral fluids;
- Positioning;
- Mouth care;
- Treatment of fever;
- Oxygen administration (if available);
- Suctioning.

Diagnostic interventions and transfer to hospital will not normally be utilized for residents who request this level of Advance Directives. No cardiopulmonary resuscitation is requested.

Level Two – Limited Therapeutic Care

Care measures will include all procedures utilized in Supportive/Comfort Care as well as the administration of antibiotics if indicated. Transfer to hospital may be arranged to provide comfort/treatment measures beyond the capability of the facility upon the direction of and at the discretion of the physician. No cardiopulmonary resuscitation is requested.

Level Three – Transfer to Acute Care Hospital

If symptoms indicate, the resident would be transferred to an acute care hospital for treatment. Assessment would be made in the acute care hospital emergency department and a decision made whether to admit the resident or return him/her to the ... facility. No cardiopulmonary resuscitation is requested and no admission to an acute care intensive care unit.

Level Four – Transfer to Acute Care with CPR

Transfer to an acute care hospital will be arranged immediately. Cardiopulmonary resuscitation (CPR) will be provided by qualified staff, if available, and by ambulance personnel.

In level-of-care forms, the patient is asked to express a wish about where, on a spectrum of interventions, they choose to sit – i.e., from non-intrusive treatments focused on comfort measures only, through to full acute care in hospital combined with resuscitation. These forms generally involve the use of tick-boxes to place the patient in a particular category of health care interventions. In the authors' experiences, level-of-care forms are generally used on admission or shortly thereafter, and are reviewed at regular intervals, in many long-term care homes throughout Ontario. As is discussed below, the authors do not recommend the use of level-of-care forms, and believe that their prevalence may contribute to some of the persistent misconceptions in Ontario around the relationship between health care consent and advance care planning.

Another common type of advance care planning involves the expression of religious, or purely values-based, wishes about future care that would not be expected to change. As noted above, a common example would be a card carried by a member of the Jehovah's Witness faith stating that the patient will not accept human blood products under any circumstances. These types of categorical wishes may or may not be solicited from patients by standard institutional policies and forms.

Lastly, many elderly patients express wishes about whether, and in what circumstances, they want to leave their home and reside (and receive care) in an institutional setting – such as a long-term care home.

While there are a myriad of potential wishes about future care, this Paper focuses largely on DNR and level-of-care wishes, as well as other wishes that are generally collected and recorded as part of health care organizations' policies and procedures.

III. CAPACITY AND INFORMED CONSENT TO TREATMENT (ONTARIO)

This section describes the general law of consent to treatment, capacity with respect to treatment decisions, and substitute decision-making in Ontario.

A. Consent to Treatment

1. *The Common Law*

The common law has long established that health care practitioners must first obtain the consent of a patient before any treatment is provided. Consent may be obtained in either written or oral form,¹⁵ or may be assumed from a patient's conduct.¹⁶ A failure to obtain consent from a patient or to disclose relevant information may lead to an action in battery. For example, in the case of *Allan v. New Mount Sinai Hospital*, the issue before the court was whether the plaintiff had consented to the administration of anaesthesia to her arm by the defendant anaesthetist, Dr. Hellman. Linden J. summarized the then common law of consent, and its application to the facts of that case, as follows:

The administration of an anaesthetic is a surgical operation. To do so would constitute a battery, unless the anaesthetist is able to establish that his patient has consented to it. An actual, subjective consent, however, is not always necessary if the doctor reasonably believes that the patient has consented. Thus, if a patient holds up an arm for a vaccination, and the doctor does one, reasonably believing that the patient is consenting to it, the patient cannot complain afterwards that there was no consent: *O'Brien v. Cunard S.S. Co., Ltd.* (1891), 28 N.E. 266. Silence by a patient, however, is not necessarily a consent. Whether a doctor can reasonably infer that a consent was given by a patient, or whether he cannot infer such consent, and must respect the wishes of the patient, as foolish as they may be, always depends on the circumstances.

...

While our Courts rightly resist advising the medical profession about how to conduct their practice, our law is clear that the consent of a patient must be obtained before any surgical procedure can be conducted. Without a consent, either written or oral, no surgery may be performed.

This is not a mere formality; it is an important individual right to have control over one's own body, even where medical treatment is involved. It is the patient, not the doctor, who decides whether surgery will be performed, where it will be done, when it will be done and by whom it will be done. Dr. Hellman, when told by Mrs. Allan not to use her left arm, had an obligation to comply with her wishes. If he thought it inadvisable, it was his duty to discuss the matter with her and try to convince her to change her mind. The expert evidence of Dr. Renwick was to the effect that this would be the usual thing to do. Dr. Hellman was not entitled to say that he knew what he was doing, and proceed to inject the needle into Mrs. Allan's left arm contrary to her express wishes.¹⁷

To be legally valid, the patient's consent must also be informed: the consent must be obtained after the nature of the treatment has been explained to the patient and the patient has been advised of the risks involved and about any available alternatives to the proposed treatment. Informed consent requires that the patient be "given the proper time and environment in order to assess the information."¹⁸

A patient retains the ability to withdraw consent. Withdrawal of consent has been deemed to be valid when a patient is capable of understanding the nature and consequences of withdrawing consent. A health practitioner who continues to provide treatment after consent has been withdrawn may also be liable for battery.¹⁹

The guiding principle at common law was, and continues to be, the concept of individual autonomy. Courts of different levels have repeatedly cited this concept,²⁰ including the Ontario Court of Appeal decision in *Malette v Shulman*:

The doctrine of informed consent holds that no medical procedure may be undertaken without the patient's consent, obtained after the patient has been provided with sufficient information to evaluate the risks and

benefits of the proposed treatment and other available options. The doctrine presupposes the patient's capacity to make a subjective treatment decision, based on her understanding of the necessary medical facts provided by the doctor and on her assessment of her own personal circumstances.²¹

In 1980, the cases of *Hopp v Lepp*²² and *Reibl v Hughes*²³ were heard by the Supreme Court of Canada and “had a monumental effect on consent litigation in Canada.”²⁴ The decision of *Hopp v Lepp* clarified the standard of informed consent such that: “even if a certain risk is a mere possibility which ordinarily need not be disclosed, yet if its occurrence carries serious consequences, as for example, paralysis or even death, it should be regarded as a material risk requiring disclosure.”²⁵ Thereafter, even remote risks of death had to be disclosed to patients.²⁶

In *Reibl v Hughes*, the patient had consented to undergo elective surgery, namely an endarterectomy to reduce future risk of stroke, but this consent was not informed. The Supreme Court established that, since the plaintiff had consented, the plaintiff could not sue for assault and battery, but could sue in negligence.²⁷ The Court reasoned that, in essence, the allegation against the physician was that the consent had been obtained negligently - by not providing the information that was pertinent, including the possibility of stroke arising from the elective surgery.²⁸ The result of this decision was that the plaintiff was required to prove causation on the negligence standard, which asks “what the average reasonable person in the patient’s position would have done in the circumstances.”²⁹ The plaintiff, Mr. Reibl, was clear that had he been provided

with the appropriate information, he would have foregone the elective surgery until such time as his retirement pension vested a year and a half later.

In the very recent Supreme Court of Canada decision in *Cuthbertson v. Rasouli* (“*Rasouli*”), McLachlin, C.J., writing for the majority of the Court reviewed the established common law backdrop in Ontario for consent to treatment:

At common law, medical caregivers must obtain a patient’s consent to the administration of medical treatment: *Reibl v. Hughes*, [1980] 2 S.C.R. 880; *Hopp v. Lepp*, [1980] 2 S.C.R. 192. The physician cannot override the patient’s wishes to be free from treatment, even if he believes that treatment is in the vital interests of the patient. The patient’s consent must be given voluntarily and must be informed, which requires physicians to ensure the patient understands the nature of the procedure, its risks and benefits, and the availability of alternative treatments before making a decision about a course of treatment. The requirement for informed consent is rooted in the concepts of an individual’s right to bodily integrity and respect for patient autonomy: see *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (C.A.).

The common law of consent to medical treatment works well for patients who have the capacity to decide on consent to treatment, in the sense of being able to understand the nature, purpose, and consequences of the proposed treatment. The patient’s autonomy interest — the right to decide what happens to one’s body and one’s life — has historically been viewed as trumping all other interests, including what physicians may think is in the patient’s best interests.

However, the traditional common law approach to medical treatment is more problematic when a patient is incapable of appreciating the nature, purpose, and consequences of the proposed treatment. As explained in *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (C.A.), at pp. 423-24, the common law doctrine of informed consent “presupposes the patient’s capacity to make a subjective treatment decision based on her understanding of the necessary medical facts provided by the doctor and on her assessment of her own personal circumstances”. When such capacity is lacking, the patient is not in a position to exercise his autonomy by consenting to or refusing medical treatment.

If a patient is incapable, disputes over consent to treatment at common law are resolved in the courts. The focus shifts from the patient’s autonomy interest, which is compromised or extinguished, to whether receiving treatment is in the best interests of the patient. In emergency

situations, where treatment is necessary to save the life or preserve the health of an incapable patient, treatment may be provided without consent: *Malette*, at p. 424. In non-emergency situations, treatment may be authorized by a court, acting under its *parens patriae* jurisdiction, or in the case of an incapable minor, by the child's parents or legal guardian. See e.g. *E. (Mrs.) v. Eve*, [1986] 2 S.C.R. 388; *B. (R.) v. Children's Aid Society of Metropolitan Toronto*, [1995] 1 S.C.R. 315, at para. 83; *Re S.D.*, [1983] 3 W.W.R. 618 (B.C. S.C.), at p. 629.³⁰

The Supreme Court's decision in *Rasouli* will be discussed in more detail below.

It is important to note the difficulties identified by the Supreme Court that arise at common law where a patient is incapable of consenting to treatment. In order to resolve many of these difficulties, the procedures for decision-making on behalf of incapable patients are now almost exclusively set out by statute in Ontario, as discussed below.

Just as consent to treatment cannot be obtained in an informational vacuum, patients cannot give informed consent to treatments that have not yet been proposed by a health practitioner. While the law of consent to treatment addresses the information that must be provided to a patient about a proposed treatment, it is primarily the law of professional negligence (and misconduct) that addresses what treatments must be proposed. Under the rubric of the applicable standard of care, the law states that:

[e]very medical practitioner must bring to his or her task a reasonable degree of skill and knowledge and must exercise a reasonable degree of care. He or she is bound to exercise that degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing.³¹

The selection of treatments to be proposed to patients is an issue of professional judgment by the health practitioner, to be reviewed on the basis of applicable professional standards.³² Informed consent to treatment necessarily involves two

decisions: the health practitioner exercising professional judgment to determine what treatment options to raise with the patient, and the patient deciding which treatment option will be consented to once the risks and benefits of treatment have been disclosed (and also deciding if any treatment options that have not been proposed by the health practitioner will be requested).

2. The Health Care Consent Act, 1996

(a) Introduction

In Ontario, consent to health care and related services is governed by the *HCCA*. This Paper focuses on the law of consent to “treatment” as that term is defined in the *HCCA*. A similar, but not identical, framework exists in the *HCCA* for consent to personal assistance services in long-term care homes and admission to care facilities (defined as long-term care homes).

(b) Consent to Treatment

Similar to the common law, the *HCCA* specifies that a health practitioner may not administer treatment unless the patient or his/her SDM has provided consent.³³ This consent may be in writing or provided orally, and may be express or implied in the circumstances.³⁴ The *HCCA* provides that consent to treatment will only be valid if:

1. The consent relates to the treatment.
2. The consent is informed.
3. The consent is given voluntarily.
4. The consent is not obtained through misrepresentation or fraud.³⁵

The *HCCA* codifies the common law test that informed consent requires disclosure of matters that a reasonable person in the same circumstances would require in order to make a decision about the treatment. The *HCCA* further particularizes the “matters” about which the patient must receive disclosure:

1. The nature of the treatment.
2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.³⁶

A health practitioner is entitled to presume that consent to treatment includes consent to reasonable variations or changes in the treatment provided there is no “significant change” to the “matters” referred to above, and it is not unreasonable to form this presumption.³⁷

Consent to treatment or a plan of treatment may be withdrawn at any time by either the patient or if incapable, his/her SDM.³⁸

The *HCCA* permits consent to be given for future treatments that have not yet been proposed to the patient by the treating health care team, provided those treatments are part of a “plan of treatment”. A plan of treatment is a plan that:

- (a) is developed by one or more health practitioners,
- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person’s current health condition, and
- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for

the withholding or withdrawal of treatment in light of the person's current health condition.³⁹

Most notably, the ability to consent to treatment not presently proposed for the patient must be tied to the patient's current health condition and the future health problems his/her current condition makes likely. In this respect, the *HCCA* limits consent to treatment to time-limited and contextualized decisions, grounded in the patient's current health condition.

In the experience of ACE and DDO, health practitioners are sometimes unfamiliar with the nuances of the statutory provisions that permit patients to give informed consent to a plan of treatment, particularly where the plan of treatment includes the withholding or withdrawal of life-sustaining interventions. As will be discussed in more detail below, it appears that the *HCCA* plan of treatment provisions are underutilized. For example, they could be employed to address needed treatment adjustments (such as middle of the night treatment changes) while still respecting the right of the patient or SDM (if incapable) to give or refuse consent to treatment and be advised of the risks and benefits of the proposed treatment. We should note that some middle of the night treatment changes would not require a new consent (even in the absences of a plan of treatment), so long as the nature, risks, side effects, and benefits of the treatment changes are not significantly different than the treatment consented to.⁴⁰

Consent to treatment is intended to be a continuous process, not a single paper form. Consent must be continuously considered and obtained through discussions with the patient or SDM. A scenario commonly encountered by the

authors is where a written consent exists (or is documented in the patient's health record from another health care organization); and the current health care team erroneously believes it cannot revisit or reconfirm the consent. While consents for particular treatments or plans of treatment can be recorded in writing, consent must always be grounded in contextualized discussions with a person. Prior consents to treatment may always be revisited or reconfirmed with patients (or if incapable their SDMs) where there is a concern that it may no longer be applicable.

Beneath the relative clarity of the requirement to obtain informed consent for proposed treatment, there has been significant litigation regarding end-of-life treatments. In *Rasouli*, the treating physicians for a patient who underwent brain surgery and who was initially in a persistent vegetative state (later upgraded to minimally conscious) took the position that the withdrawal of life support that was of no medical benefit to the patient was not "treatment" under the HCCA – and as such they were not required to obtain consent to withdraw life support.⁴¹ This case hinged on the definition of "treatment" under the *HCCA*:

"treatment" means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan, but does not include,

(a) the assessment for the purpose of this Act of a person's capacity with respect to a treatment, admission to a care facility or a personal assistance service, the assessment for the purpose of the *Substitute Decisions Act, 1992* of a person's capacity to manage property or a person's capacity for personal care, or the assessment of a person's capacity for any other purpose,

- (b) the assessment or examination of a person to determine the general nature of the person's condition,
- (c) the taking of a person's health history,
- (d) the communication of an assessment or diagnosis,
- (e) the admission of a person to a hospital or other facility,
- (f) a personal assistance service,
- (g) a treatment that in the circumstances poses little or no risk of harm to the person,
- (h) anything prescribed by the regulations as not constituting treatment.⁴² [Emphasis added]

Ultimately, the majority of the Supreme Court of Canada decided that the removal of life support constitutes treatment as it would be done for a “health-related purpose.” The majority explained its ruling as follows:

In summary, withdrawal of life support aims at the health-related purpose of preventing suffering and indignity at the end of life, often entails physical interference with the patient's body, and is closely associated with the provision of palliative care. Withdrawal of life support is inextricably bound up with care that serves health-related purposes and is tied to the objects of the Act. By removing medical services that are keeping a patient alive, withdrawal of life support impacts patient autonomy in the most fundamental way. The physicians' attempt to exclude withdrawal of life support from the definition of “treatment” under s. 2(1) of the *HCCA* cannot succeed.⁴³

It is important to note that the ratio of this decision may not apply to all other cases involving the withdrawal of medical interventions or treatment. The McLachlin, C.J. was careful to limit the scope of the majority decision:

These considerations lead me to conclude that “treatment” in the *HCCA* should be understood as extending to withdrawal of life support in the situation at issue here and as that process is described in these proceedings. This case does not stand for the proposition that consent is

required under the *HCCA* for withdrawals of other medical services or in other medical contexts.⁴⁴

Given the broad interpretation of “health-related purpose” under the *HCCA* in *Rasouli*, the reasoning of the Supreme Court would appear to be equally applicable in the context of the withdrawal of other treatments. However, the above paragraph of the majority decision suggests otherwise. At present, the applicability of *Rasouli* beyond the withdrawal of life support remains unclear.

(c) Emergency Treatment

With limited exceptions, in an emergency health practitioners may provide treatment without consent. Importantly, the *HCCA* does not provide that consent to treatment will be implied in an emergency. Consent is simply not required before providing emergency treatment. However, health practitioners cannot provide treatment, even in an emergency, if they are aware that a patient who is 16 years or older expressed a wish while capable to refuse the treatment (and, if the patient is capable at the time of the emergency, health practitioners cannot provide treatment if they are of the opinion that there is a reason to believe the patient does not want the treatment).⁴⁵

The health practitioner is not obliged to blindly follow any prior wish relative to the proposed treatment in an emergency. Health practitioners should use judgment in determining whether a prior capable wish is applicable to the emergency treatment proposed; they are protected from liability where they provide emergency treatment without consent in good faith.⁴⁶ Similarly, where an SDM refuses treatment in an emergency on behalf of an incapable patient, and

the health practitioner is of the opinion that the SDM has not complied with his/her obligations, discussed below, the health practitioner may provide treatment despite the refusal.⁴⁷

This exception to the requirement to obtain consent does not apply in all circumstances where the patient is in peril. This exception applies only when a capable patient is unable to communicate, or (for an incapable patient) there would be undue delay in speaking with an incapable patient's SDM to obtain consent. Once this exception no longer applies, the health practitioner is required to obtain consent to treatment in the usual course from a patient or SDM.⁴⁸

Even where this exception initially applies, treatment can only be continued until the patient can communicate or the SDM is located. The health practitioner is required to take reasonable steps to enable communication or to locate the SDM.⁴⁹

(d) Consent to Admission to a Care Facility

As noted above, the *HCCA* also contains provisions governing the admission of a person to a “care facility”, a term defined in the act as a long-term care home, or any other facility prescribed by regulation.⁵⁰ There are no other facilities prescribed by regulation as a care facility at this time.

The *HCCA* prescribes the process for admission to a care facility where the person is incapable and their consent is otherwise required.⁵¹ The *Long-Term Care Homes Act, 2007* specifies that consent is required for admission, and also

contains consent provisions mirroring those applicable to treatment under the *HCCA*.⁵²

Similar to the provisions for emergency treatment, in a “crisis” the *HCCA* permits admission to a care facility without the consent of the patient where the patient has been found incapable by an evaluator, and the person authorizing admission to the care facility forms the opinion that the incapable patient requires immediate admission and it is not reasonably possible to obtain consent. In these circumstances, the person responsible for admission to the care facility must seek consent from the patient’s SDM after admission.⁵³

(f) Consent to Personal Assistance Services

Similar to admission to a care facility, the *HCCA* contains provisions governing capacity and substitute consent with regard to “personal assistance services”, a defined term meaning:

assistance with or supervision of hygiene, washing, dressing, grooming, eating, drinking, elimination, ambulation, positioning or any other routine activity of living, and includes a group of personal assistance services or a plan setting out personal assistance services to be provided to a person, but does not include anything prescribed by the regulations as not constituting a personal assistance service.⁵⁴

These provisions are only applicable to personal assistance services provided in a long-term care home.⁵⁵

B. Capacity to Consent or Refuse Treatment

1. Test for Capacity

In Ontario, all persons are presumed to be capable to make decisions with respect to treatment, admission to a care facility, and personal assistance services.⁵⁶ Health practitioners may rely on this presumption of capacity unless they have reasonable grounds to believe that the person is incapable.⁵⁷ They are also protected from liability under the *HCCA* if they make this (and other) decisions under the *HCCA* on reasonable grounds and in good faith.⁵⁸

The importance of making treatment decisions for oneself, and the competing interest of protecting those patients who lack capacity, was recognized by the Supreme Court of Canada in the seminal case of *Starson v.*

Swayze:

The right to refuse unwanted medical treatment is fundamental to a person's dignity and autonomy. This right is equally important in the context of treatment for mental illness: see *Fleming v. Reid* 1991 CanLII 2728 (ON CA), (1991), 4 O.R. (3d) 74 (C.A.), per Robins J.A., at p. 88:

Few medical procedures can be more intrusive than the forcible injection of powerful mind-altering drugs which are often accompanied by severe and sometimes irreversible adverse side effects.

Unwarranted findings of incapacity severely infringe upon a person's right to self-determination. Nevertheless, in some instances the well-being of patients who lack the capacity to make medical decisions depends upon state intervention: see *E. (Mrs.) v. Eve*, 1986 CanLII 36 (SCC), [1986] 2 S.C.R. 388, at p. 426. The Act aims to balance these competing interests of liberty and welfare: see *B. F. Hoffman*, *The Law of Consent to Treatment in Ontario* (2nd ed. 1997), at p. 3....⁵⁹

Capacity is defined under the *HCCA* as a two-part concept, relating to both the ability to understand relevant information, and the ability to appreciate

the reasonably foreseeable consequences of a decision or lack of a decision.

Both requirements must be satisfied in order for the patient to be capable:

Capacity

4. (1) A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.⁶⁰

Capacity is not a global condition of the patient, but instead depends on each proposed treatment put to the patient for a decision by a health practitioner. The *HCCA* recognizes that capacity for a particular treatment decision may change over time and that, with the return of capacity, the decision of the now capable patient governs.⁶¹

The Supreme Court of Canada explained the intricacies of the test for capacity in *Starson*, and specifically noted that capacity did not require that the patient either agree with his diagnosis, or that the patient's decision be in keeping with his own best interests:

....Capacity involves two criteria. First, a person must be able to understand the information that is relevant to making a treatment decision. This requires the cognitive ability to process, retain and understand the relevant information. There is no doubt that the respondent satisfied this criterion. Second, a person must be able to appreciate the reasonably foreseeable consequences of the decision or lack of one. This requires the patient to be able to apply the relevant information to his or her circumstances, and to be able to weigh the foreseeable risks and benefits of a decision or lack thereof. The Board's finding of incapacity was based on their perception of Professor Starson's failure in this regard.

Before turning to an analysis of the reviewing judge's decision, two important points regarding this statutory test require comment. First, a patient need not agree with the diagnosis of the attending physician in

order to be able to apply the relevant information to his own circumstances. Psychiatry is not an exact science, and “capable but dissident interpretations of information” are to be expected: see Weisstub Report, *supra*, at p. 229. While a patient need not agree with a particular diagnosis, if it is demonstrated that he has a mental “condition”, the patient must be able to recognize the possibility that he is affected by that condition. Professor Weisstub comments on this requirement as follows (at p. 250, note 443):

Condition refers to the broader manifestations of the illness rather than the existence of a discrete diagnosable pathology. The word condition allows the requirement for understanding to focus on the objectively discernible manifestations of the illness rather than the interpretation that is made of these manifestations.

As a result, a patient is not required to describe his mental condition as an “illness”, or to otherwise characterize the condition in negative terms. Nor is a patient required to agree with the attending physician’s opinion regarding the cause of that condition. Nonetheless, if the patient’s condition results in him being unable to recognize that he is affected by its manifestations, he will be unable to apply the relevant information to his circumstances, and unable to appreciate the consequences of his decision.

Secondly, the Act requires a patient to have the ability to appreciate the consequences of a decision. It does not require actual appreciation of those consequences. The distinction is subtle but important: see L. H. Roth, A. Meisel and C. W. Lidz, “Tests of Competency to Consent to Treatment” (1977), 134 *Am. J. Psychiatry* 279, at pp. 281-82, and Weisstub Report, *supra*, at p. 249. In practice, the determination of capacity should begin with an inquiry into the patient’s actual appreciation of the parameters of the decision being made: the nature and purpose of the proposed treatment; the foreseeable benefits and risks of treatment; the alternative courses of action available; and the expected consequences of not having the treatment. If the patient shows an appreciation of these parameters — regardless of whether he weighs or values the information differently than the attending physician and disagrees with the treatment recommendation — he has the ability to appreciate the decision he makes: see Roth, Meisel and Lidz, *supra*, at p. 281.

However, a patient’s failure to demonstrate actual appreciation does not inexorably lead to a conclusion of incapacity. The patient’s lack of appreciation may derive from causes that do not undermine his ability to appreciate consequences. For instance, a lack of appreciation may reflect the attending physician’s failure to adequately inform the patient of the decision’s consequences: see the Weisstub Report, *supra*, at p. 249.

Accordingly, it is imperative that the Board inquire into the reasons for the patient's failure to appreciate consequences. A finding of incapacity is justified only if those reasons demonstrate that the patient's mental disorder prevents him from having the ability to appreciate the foreseeable consequences of the decision. [Emphasis in original]⁶²

A health practitioner proposing treatment has an obligation to determine whether the patient is capable or incapable of consenting to the proposed treatment.

Where a patient has been found to be incapable under the *HCCA*, the health practitioner shall give the patient rights information about the consequences of the finding of incapacity as specified by the governing body of the health practitioner's profession.⁶³ For example, the College of Physicians and Surgeons of Ontario's policy on *Consent to Medical Treatment* provides the following guidance to physicians on the information that should be communicated to the incapable patient:

Even when there is a substitute decision-maker, a physician must still involve the patient. The College advises the physician to take the following steps:

1. Tell the incapable patient that a substitute decision-maker will assist the patient in understanding the proposed treatment and will be responsible for making the final decision.
2. Involve the incapable patient, to the extent possible, in discussions with the substitute decision-maker.
3. If the patient disagrees with the need for a substitute decision-maker, or disagrees with the involvement of the present substitute, the physician must advise the patient of his or her options. These include finding another substitute of the same or more senior rank, and/or applying to the Consent and Capacity Board for a review of the finding of incapacity.²¹
4. Reasonably assist the patient if he or she expresses a wish to exercise the options outlined above in paragraph 3.⁶⁴

Notably, the *HCCA* does not require that the patient receive advice from a rights adviser (an actual person): only rights information is required to be provided by the proposing health practitioner. This is in contrast to the provisions for patients in a psychiatric facility under the *Mental Health Act*, who receive rights advice upon numerous changes of legal status, including upon a finding of treatment incapacity, incapacity to manage property, and involuntary detention.⁶⁵

In addition to health practitioners' obligations to patients found incapable, the *HCCA* has also been interpreted by the Ontario Court of Appeal as requiring that health practitioners ensure that SDMs understand their decision-making role and obligations.⁶⁶

2. Challenging a Finding of Incapacity

Patients found incapable under the *HCCA* may apply to the Consent and Capacity Board (the "CCB") for a review of that finding. The CCB is an independent, quasi-judicial body with specialized jurisdiction over many matters, including consent to treatment under the *HCCA*, findings of financial incapacity, involuntary admission to a psychiatric facility on a Form 3 or 4 under the *Mental Health Act*, and capacity to consent to collect, use and disclose personal health information under the *Personal Health Information Protection Act*.

Patients subject to guardianship of the person, or who have executed a power of attorney for personal care waiving the patient's right to apply for a review of the finding of incapacity (often referred to as a 'Ulysses clause'⁶⁷), may not apply to the CCB for a review of the finding of incapacity.⁶⁸ Powers of

attorney for personal care containing Ulysses clauses are relatively uncommon and are only effective if they comply with specific requirements in the *SDA*:

1. At the time the power of attorney was executed or within 30 days afterwards, the grantor made a statement in the prescribed form indicating that he or she understood the effect of the provision and of subsection (4) [which addresses revocation].
2. Within 30 days after the power of attorney was executed, an assessor made a statement in the prescribed form,
 - i. indicating that, after the power of attorney was executed, the assessor performed an assessment of the grantor's capacity,
 - ii. stating the assessor's opinion that, at the time of the assessment, the grantor was capable of personal care and was capable of understanding the effect of the provision and of subsection (4) [which addresses revocation], and
 - iii. setting out the facts on which the opinion is based.⁶⁹

The *SDA* requires extra procedural protections for grantors of powers of attorneys containing exceptional clauses, such as the requirement that the capacity of the grantor be confirmed at, or 30 days after, execution.

At a CCB hearing reviewing a health practitioner's finding of incapacity, the onus is always on the health practitioner proposing treatment to prove a lack of capacity on a balance of probabilities. In *Starson*, the Supreme Court explained the mandate of the CCB when hearing an application for review of a finding of incapacity:

The legislative mandate of the Board is to adjudicate solely upon a patient's capacity. The Board's conception of the patient's best interests is irrelevant to that determination. As the reviewing judge observed, "[a] competent patient has the absolute entitlement to make decisions that any reasonable person would deem foolish" (para. 13). This point was aptly stated by Quinn J. in *Koch (Re)* 1997 CanLII 12138 (ON SC), (1997), 33 O.R. (3d) 485 (Gen. Div.), at p. 521:

The right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake.

In this case, the only issue before the Board was whether Professor Starson was capable of making a decision on the suggested medical treatment. The wisdom of his decision has no bearing on this determination.

The law presumes a person is capable to decide to accept or reject medical treatment: s. 4(2) of the Act. At a capacity hearing, the onus is on the attending physician to prove that the patient is incapable. I agree with the Court of Appeal that proof is the civil standard of a balance of probabilities. As a result, patients with mental disorders are presumptively entitled to make their own treatment decisions. Professor D. N. Weisstub, in his *Enquiry on Mental Competency: Final Report (1990)*, at p. 116 (“Weisstub Report”), notes the historical failure to respect this presumption:

The tendency to conflate mental illness with lack of capacity, which occurs to an even greater extent when involuntary commitment is involved, has deep historical roots, and even though changes have occurred in the law over the past twenty years, attitudes and beliefs have been slow to change. For this reason it is particularly important that autonomy and self determination be given priority when assessing individuals in this group.

The Board must avoid the error of equating the presence of a mental disorder with incapacity. Here, the respondent did not forfeit his right to self-determination upon admission to the psychiatric facility: see *Fleming v. Reid*, *supra*, at p. 86. The presumption of capacity can be displaced only by evidence that a patient lacks the requisite elements of capacity provided by the Act.⁷⁰

The *HCCA* restricts the ability of a patient to bring repeated applications challenging a finding of incapacity. Where the CCB has confirmed a finding that a patient is incapable with respect to a treatment, that patient must wait six months before requesting another review of the finding of incapacity, subject to leave granted by the CCB.⁷¹ Of course, where a formerly incapable patient’s capacity returns, the health practitioner should revoke the finding of incapacity and obtain

consent directly from the patient (regardless of whether the patient has the legal right to bring an application to the CCB). In the authors' experience, this does not always occur.

The *HCCA* contains provisions governing the procedure for determining when treatment may be administered to a patient who has been found incapable, but who intends to challenge that finding (or appoint a representative) and the application to the CCB is not prohibited. In these circumstances, treatment shall not begin (and the health practitioner has an obligation to ensure that reasonable steps are taken to ensure that treatment is not begun), until:

- (a) 48 hours have elapsed since the health practitioner was first informed of the intended application to the Board without an application being made;
- (b) the application to the Board has been withdrawn;
- (c) the Board has rendered a decision in the matter, if none of the parties to the application before the Board has informed the health practitioner that he or she intends to appeal the Board's decision; or
- (d) if a party to the application before the Board has informed the health practitioner that he or she intends to appeal the Board's decision,
 - (i) until the period for commencing the appeal has elapsed without an appeal being commenced, or
 - (ii) until the appeal of the Board's decision has been finally disposed of.⁷²

A health practitioner can still provide treatment in an emergency, with limited exceptions, as described above, for a patient found incapable and who intends to challenge that finding.⁷³

Where the CCB confirms the finding of incapacity with respect to treatment, and the patient commences an appeal from that CCB decision to the

Court, the Court may make an order permitting treatment to be administered, notwithstanding the pending appeal, if the following conditions are met:

The court is satisfied,

(a) that,

(i) the treatment will or is likely to improve substantially the condition of the person to whom it is to be administered, and the person's condition will not or is not likely to improve without the treatment, or

(ii) the person's condition will or is likely to deteriorate substantially, or to deteriorate rapidly, without the treatment, and the treatment will or is likely to prevent the deterioration or to reduce substantially its extent or its rate;

(b) that the benefit the person is expected to obtain from the treatment outweighs the risk of harm to him or her;

(c) that the treatment is the least restrictive and least intrusive treatment that meets the requirements of clauses (a) and (b); and

(d) that the person's condition makes it necessary to administer the treatment before the final disposition of the appeal.⁷⁴

3. Admission to a Care Facility and Provision of Personal Assistance Services

The test for capacity in the *HCCA* applies to admission to a care facility, consent to treatment, and the provision of personal assistance services. The *HCCA* provides that an "evaluator" who finds a person incapable with respect to admission to a care facility shall provide information to the patient explaining the consequences of the finding of incapacity in the manner specified by their professional governing body.⁷⁵ Evaluators are a class of individuals defined under the *HCCA* as members of many of the regulated health professions (including social workers).⁷⁶ The provisions relating to a patient's right to apply to the CCB for a review of the finding of incapacity with respect to admission to a

care facility and forestalling admission to a care facility pending a decision of the CCB are substantially similar to the provisions relating to treatment.⁷⁷

The provisions of the *HCCA* with respect to capacity to make a decision to receive personal assistance services in a long-term care home (and to challenge that decision before the CCB) are substantially similar to the provisions relating to capacity for admission to a care facility. One notable exception is that the *HCCA* does not contain provisions forestalling the provision of personal assistance services pending an application to the CCB.⁷⁸

4. Capacity for Personal Care under the Substitute Decisions Act, 1992

The *SDA* contains a procedure for assessing capacity to make decisions relating to personal care. The two-part test for capacity under the *SDA* is identical, with necessary modifications, to that in the *HCCA*.⁷⁹

Importantly, the test for capacity for “personal care” under the *SDA* does not override the capacity regime under the *HCCA*. The *SDA* contains a carve-out stating that, where an attorney for personal care is authorized to make a decision under the *HCCA*, the *HCCA* provisions will apply to that decision. Where the *HCCA* does not govern a personal care decision, the provisions of the *SDA* will apply:

When power of attorney effective

49. (1) A provision in a power of attorney for personal care that confers authority to make a decision concerning the grantor’s personal care is effective to authorize the attorney to make the decision if,

- (a) the *Health Care Consent Act, 1996* applies to the decision and that Act authorizes the attorney to make the decision; or

(b) the *Health Care Consent Act, 1996* does not apply to the decision and the attorney has reasonable grounds to believe that the grantor is incapable of making the decision, subject to any condition in the power of attorney that prevents the attorney from making the decision unless the fact that the grantor is incapable of personal care has been confirmed. 1996, c. 2, s. 32 (1).⁸⁰

Where the *HCCA* does not apply to a personal care decision, it is important to note that an attorney may simply begin to exercise his/her authority over personal care provided he/she has reasonable grounds to believe the grantor is incapable – unless the grantor has specified in the power of attorney for personal care that it only becomes effective once incapacity is confirmed. There is no overarching requirement for incapacity to be confirmed by a third party before an attorney begins to exercise authority under the *SDA*. A grantor may specify the method of confirmation, including which individual is to make the determination of incapacity.⁸¹ Where no method is specified in the power of attorney for personal care, the *SDA* specifies that an “assessor” will confirm incapacity, but the grantor may specify the factors to be considered by the assessor.⁸² An “assessor” is defined by regulation as a member of specified health colleges, who has completed a course and met other requirements.⁸³

An assessment by a capacity “assessor” is not always required for an attorney for personal care to begin exercising his/her authority. However, where an assessor is to perform an assessment for capacity, the grantor has the right to refuse to be assessed.⁸⁴ When conducting an assessment, assessors are required to explain to the person being assessed:

- (a) the purpose of the assessment;
- (b) the significance and effect of a finding of capacity or incapacity; and
- (c) the person's right to refuse to be assessed.⁸⁵

However, the right to refuse an assessment by an assessor can be overridden by a Ulysses clause (discussed above) in a power of attorney for personal care, or by court order.⁸⁶ Most importantly, the right to refuse an assessment of capacity does not apply to decisions covered by the *HCCA* (i.e. patients attending a hospital for treatment cannot refuse to have their capacity to consent to treatment assessed by a treating health practitioner while still requesting that treatment be provided).

C. Substitute Decision-Making

1. Introduction

Where consent is required for the provision of treatment, admission to a care facility, or the provision of personal assistance services, and the patient has been found incapable with respect to that decision, consent may be obtained from the patient's SDM.

The *HCCA* contains provisions for determining which individual is the correct SDM, and the basis upon which the SDM is to decide to give or refuse consent on behalf of the incapable person.

2. The Hierarchy

All incapable patients have an SDM, whether they know it or not, and whether they want one or not. According to the *HCCA*, the following individuals

may give or refuse consent to treatment on behalf of an incapable person. These individuals are ranked in a hierarchy, with decisions of those individuals higher on the list prevailing over decisions made by individuals lower on the list.⁸⁷

1. Guardian of person with authority for treatment

This person is someone who has an order from the Superior Court of Ontario naming him/her the guardian of the person for the incapable person under the *SDA*.⁸⁸ It is important to note that this is not necessarily the same person as the Guardian for Property of an incapable person or the Statutory Guardian of the incapable person, who may only have authority over the person's money/property.

2. Attorney for personal care with authority for health care

This person is the attorney as named in a power of attorney for personal care under the *SDA* (discussed below).⁸⁹

3. Representative appointed by CCB

This person is someone who has been appointed by the Consent and Capacity Board to make the decision currently required by the incapable person regarding treatment, admission to a long-term care home, or personal assistance services in a long-term care home. The CCB may also authorize the Representative to make a wider range of decisions for the incapable person related to treatment, admission to a long-term care home, or personal assistance services.⁹⁰

4. “Spouse” or “partner”

Two persons are “spouses” if they are

(a) married to each other; or

(b) living in a conjugal relationship outside marriage and,

(i) have cohabited for at least one year,

- (ii) are together the parents of a child, or
- (iii) have together entered into a cohabitation agreement under section 53 of the *Family Law Act*.⁹¹

They can be spouses if they are both of the same sex or the opposite sex. They are not spouses if they are not yet divorced, but are living separate and apart within the meaning of the *Divorce Act* (Canada).

Two people are “partners” if they have lived together for at least one year and have a close personal relationship that is of primary importance in both persons’ lives.⁹² This can include friends who have lived together for at least one year (a non-sexual relationship) and have a close personal relationship that is of primary importance in both their lives. However, just because individuals are roommates or housemates, they may not be partners because they may not have a close personal relationship that is of “primary importance” in both their lives. Relatives living together, for example a parent and adult child, may meet this definition.

5. Child or parent or Children's Aid Authority (CAS) or other person lawfully entitled to give or refuse consent to treatment in place of parent

This definition does not include a parent with right of access only. If CAS, or another person, is standing in place of a parent, this does not include the parent. For a child to act as SDM, he/she must be at least 16 years of age, unless he/she is the parent of a child for whom he/she is acting (e.g., the 15-year old mother of an infant would be entitled to act on behalf of her child).

6. Parent with right of access only

7. Brother or sister

8. Any other relative

People who do not meet the above definitions but are related by blood, marriage or adoption, are relatives.⁹³

Where there is a conflict between two equally ranked persons in the hierarchy who meet the requirements to act jointly as SDMs, the Public Guardian and Trustee “shall make the decision in their stead.”⁹⁴

3. Requirements to be SDM

Individuals ranked on the hierarchy may only give or refuse consent provided that they meet the below requirements:

- (a) the proposed SDM is capable with respect to the treatment;
- (b) the proposed SDM is at least 16 years old, unless he or she is the incapable person’s parent;
- (c) the proposed SDM is not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf;
- (d) the proposed SDM is available;
- (e) the proposed SDM is willing to assume the responsibility of giving or refusing consent; and.
- (f) there is no person higher on the ranked list of substitute decision makers SDMs who meets these requirements.⁹⁵

The requirement that the SDM be capable frequently causes confusion. It is the responsibility of the health practitioner proposing treatment to obtain consent from a capable SDM. The health practitioner may have limited knowledge about the SDM, and not have a health history of this individual. However, the health practitioner should make inquiries of SDMs to determine if they are capable. If an individual is incapable, the health practitioner must move to the next highest SDM in the hierarchy who meets the above requirements.

An SDM found incapable by a health practitioner does not have a statutory right under the *HCCA* to make an application to the CCB for a review of the finding of incapacity. Where an SDM is found incapable, his/her best remedy is to apply to the CCB to be appointed as a representative on behalf of the incapable patient (a “Form C” application). Under the *HCCA*, a representative may be appointed for an incapable patient by the CCB if:

1. The incapable person does not object to the appointment.
2. The representative consents to the appointment, is at least 16 years old and is capable with respect to the treatments or the kinds of treatment for which the appointment is made.
3. The appointment is in the incapable person’s best interests.⁹⁶

On an application to be a representative the CCB will determine whether the proposed representative is capable to make the decision for the patient, and will effectively resolve the dispute over the health practitioner’s determination of the SDM’s incapacity.⁹⁷

The requirement that the SDM be “available” is defined under the *HCCA*. A person is available if “it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal.”⁹⁸ The SDM need not be physically present in order to be available (a fact that is arguably more important in this day of connectivity, where a person may be at a great geographical distance but still be able to participate in treatment decisions).

There is one exception to the general rule that only the person highest on the hierarchy (and who meets the above requirements) may give consent on

behalf of the incapable patient. A family member present or contacted may consent or refuse consent if he or she believes that:

- (a) no person higher or with the same ranking exists; or,
- (b) if a higher ranking person exists, that person is not a guardian of the person, attorney for personal care, or Board appointed representative with authority to consent AND that person would not object to him or her making the decision.⁹⁹

Where no person on the hierarchy meets the requirements to act as an SDM, the Public Guardian and Trustee “shall” make the decision to give or refuse consent to treatment or admission to a care facility.¹⁰⁰ However, the Public Guardian and Trustee is not required to make a decision relating to the provision of personal assistance services – the *HCCA* provides that the Public Guardian and Trustee “may” make this decision,¹⁰¹ (a discretion echoed in the *Personal Health Information Protection Act* with respect to consent to the collection, use and disclosure of personal health information).¹⁰² Where the Public Guardian and Trustee declines to make a decision relating to the provision of personal assistance services, an individual would likely have to apply to court to be the incapable patient’s guardian of the person with authority to make decisions regarding personal assistance services, or apply to the CCB to be the incapable patient’s representative, and thereby pull rank on the hierarchy of SDMs.¹⁰³

4. Obligations of the SDM

The *HCCA* specifies the obligations of SDMs and the factors they shall consider in making a decision on behalf of an incapable person.

If the SDM is aware of prior “wishes” that are “applicable to the circumstances”, expressed when the patient was aged 16 or older and capable, the SDM is required to act in accordance with these wishes. However, where there is no prior capable wish expressed by the patient, the SDM shall make a decision based on the patient’s best interests,¹⁰⁴ taking into consideration the following factors:

- (a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;
- (b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and
- (c) the following factors:
 - 1. Whether the treatment is likely to,
 - i. improve the incapable person’s condition or well-being,
 - ii. prevent the incapable person’s condition or well-being from deteriorating, or
 - iii. reduce the extent to which, or the rate at which, the incapable person’s condition or well-being is likely to deteriorate.
 - 2. Whether the incapable person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment.
 - 3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
 - 4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.¹⁰⁵

In giving or refusing consent on behalf of the incapable patient, the SDM is entitled to receive all of the same information the patient would have been entitled to receive in order to give or refuse informed consent.¹⁰⁶ As noted above, the Ontario Court of Appeal has held that health practitioners also have an

obligation to ensure that SDMs are informed of their decision-making obligations in consenting or refusing treatment, set out above.¹⁰⁷

There is a two-stage analysis for making decisions on behalf of an incapable person: first, the SDM must determine if there are prior capable wishes that must be followed and, if there are none, the SDM must determine what decision is in the patient's best interests. The two-stage analysis for making decisions on behalf of incapable persons under the *HCCA*, and the duties of SDMs, was explained by the Supreme Court in *Rasouli*:

Under the *HCCA*, the substitute decision-maker does not have *carte blanche* to give or refuse consent. He or she must comply with the requirements of s. 21 of the Act, which contemplates two situations. The first is where the substitute decision-maker knows of a prior expressed wish by the patient which is applicable to the circumstances. The second is where there is no such wish, in which case the substitute decision-maker "shall act in the incapable person's best interests".

(1) Prior Expressed Wishes

If the substitute decision-maker knows of a prior wish regarding treatment that the patient expressed when capable and over 16 years old, and that is applicable in the circumstances, the wish must be followed: s. 21(1). This reflects the patient's autonomy interest, insofar as it is possible.

While the *HCCA* gives primacy to the prior wishes of the patient, such wishes are only binding if they are applicable to the patient's current circumstances. This qualification is no mere technicality. As the Ontario Court of Appeal held in *Conway v. Jacques* (2002), 59 O.R. (3d) 737, at para. 31:

. . . prior capable wishes are not to be applied mechanically or literally without regard to relevant changes in circumstances. Even wishes expressed in categorical or absolute terms must be interpreted in light of the circumstances prevailing at the time the wish was expressed.

Needless to say, where an incapable patient has expressed a prior wish that life support not be withdrawn, the intended meaning and scope of the wish must be carefully considered: see Fleming, at p. 94. The question is

whether, when the wish was expressed, the patient intended its application in the circumstances that the patient now faces.... Changes in the patient's condition, prognosis, and treatment options may all bear on the applicability of a prior wish: Conway, at paras. 37-38. ...

A prior wish need not identify every possible future development in order to be applicable: Scardoni, at para. 74; K.M.S. (Re), 2007 CanLII 29956 (Ont. C.C.B.). However, a wish that is unclear, vague, or lacks precision may be held inapplicable to the circumstances. On this basis, the Board has found there were no prior wishes relating to life support applicable to the existing circumstances in numerous cases: D.D. (Re), 2013 CanLII 18799; P. (D), Re, 2010 CarswellOnt 7848; E.B. (Re), 2006 CanLII 46624; G. (Re); E. (Re), 2009 CanLII 28625; H.J. (Re), 2003 CanLII 49837. I have been unable to locate any case in which there was a prior expressed wish opposing withdrawal of life support that was held to be applicable and therefore binding in the circumstances.

If it is unclear whether a prior wish is applicable, the substitute decision-maker or physician may seek directions from the Board: s. 35. Alternately, if the substitute decision-maker acts on a prior wish that the physician believes is not applicable, the physician may challenge the consent decision before the Board: s. 37. The physician's submissions on the patient's condition, prognosis, and any adverse effects of maintaining life support will be relevant to the Board's assessment of applicability.

In addition, either the substitute decision-maker or physician may apply to the Board for permission to depart from prior wishes to refuse treatment: s. 36. The Board may grant permission where it is satisfied that the incapable person, if capable, would probably give consent because of improvement in the likely result of the treatment since the wish was expressed: s. 36(3).

I note that the HCCA also provides that the substitute decision-maker is not required to comply with an expressed prior wish if "it is impossible to comply with the wish": s. 21(1)2. [...]

(2) The Best Interests of the Patient

If the substitute decision-maker is not aware of an expressed prior wish of the patient or if the wish is not applicable to the circumstances, the substitute decision-maker must make her consent decision based on the best interests of the patient, according to the criteria set out in s. 21(2). These criteria include the medical implications of treatment for the patient, the patient's well-being, the patient's values, and any prior expressed wishes that were not binding on the substitute decision-maker. This legislative articulation of the best interests of the patient aims at advancing the values that underpin the HCCA: enhancing patient autonomy and ensuring appropriate medical treatment.

The substitute decision-maker is not at liberty to ignore any of the factors within the best interests analysis, or substitute her own view as to what is in the best interests of the patient. She must take an objective view of the matter, having regard to all the factors set out, and decide accordingly. This is clear from the mandatory wording of the opening portion of s. 21(2): the decision-maker “shall take into consideration” the listed factors. ... The intent of the statute is to obtain a decision that, viewed objectively, is in the best interests of the incapable person.¹⁰⁸

The *HCCA* provides a mechanism to ensure that the SDM is complying with his/her obligations to the patient under this two-stage analysis: an application to the CCB by the health practitioner under a “Form G”. This application is discussed in more detail below.

5. Powers of Attorney for Personal Care and Guardians of the Person

Capable patients, who are dissatisfied with their default statutory SDM under the *HCCA*, are not required to accept that future decisions will be made for them by, for example, an estranged relative. They can choose someone else. The *SDA* contains provisions permitting a patient to create a power of attorney for personal care designating an attorney to make personal care decisions (sometimes called a ‘proxy directive’). An attorney for personal care will rank above everyone in the hierarchy set out in the *HCCA* (except a guardian of the person).¹⁰⁹

Under Part II of the *SDA*, a person may give a written power of attorney for personal care authorizing the person (or persons) named to make decisions on behalf of the person granting the power of attorney. This power of attorney for personal care may also contain “instructions with respect to the decisions the

attorney is authorized to make.”¹¹⁰ These “instructions” are to be interpreted by the SDM as “wishes” for decisions under the *HCCA*.¹¹¹ The power of attorney for personal care must be in writing and be signed by two witnesses. In order to create an effective power of attorney for personal care, the patient must be capable, meaning that he/she must:

- (a) have the ability to understand whether the proposed attorney has a genuine concern for their welfare; and
- (b) appreciate that the patient may need to have the proposed attorney make decisions for the person.¹¹²

A power of attorney for personal care that confers authority to make a decision concerning the grantor’s personal care will be effective for all decisions under the *HCCA*.¹¹³

Beyond the powers of other default SDMs under the *HCCA*, the *SDA* also provides that a power of attorney may give authority to an attorney:

- (a) to use force to determine whether the patient is incapable,
- (b) to use force to apprehend the patient and take them to a place of treatment, and
- (c) to waive the patient’s right to apply to the consent and capacity board to review a finding of incapacity.¹¹⁴

However, as noted above, these powers may only be included in a power of attorney for personal care if:

1. At the time the power of attorney was executed or within 30 days afterwards, the grantor made a statement in the prescribed form indicating that he or she understood the effect of the provision and of subsection (4) [which addresses revocation].
2. Within 30 days after the power of attorney was executed, an assessor made a statement in the prescribed form,

- i. indicating that, after the power of attorney was executed, the assessor performed an assessment of the grantor's capacity,
- ii. stating the assessor's opinion that, at the time of the assessment, the grantor was capable of personal care and was capable of understanding the effect of the provision and of subsection (4) [which addresses revocation], and
- iii. setting out the facts on which the opinion is based.¹¹⁵

Where powers with a greater potential for abuse are granted to attorneys, the *SDA* protects the grantor by ensuring their capacity is confirmed through a special type of assessment.

The highest rung on the hierarchy of SDMs in the *HCCA* belongs to guardians of the person. The *SDA* sets out the procedure for appointing guardians of the person, and also provides for the powers of those guardians. Guardians of the person can only be appointed by the Court on an application.¹¹⁶ A full examination of guardianship proceedings is beyond the scope of this Paper, but it is important to note that a guardian of the person will not necessarily have authority to make health-care decisions on behalf of an incapable patient, unless the court order specifically provides this power.¹¹⁷

Both attorneys for personal care and guardians of the person are required to act diligently and in good faith. For any decisions governed by the *HCCA*, attorneys for personal care and guardians of the person appointed under the *SDA* are required to act in accordance with their obligations under the *HCCA*, set out above.¹¹⁸

6. Applications with respect to Substitute Decision-Making

(a) Section 37 Applications

Section 37 of the *HCCA* permits a health practitioner to bring an application (called a “Form G”) to determine whether an SDM is complying with his/her obligations under the *HCCA*. In some cases, these applications involve a fact scenario in which a health practitioner has proposed a palliative plan of care for a terminally ill patient, and the SDM has refused – arguing that the patient would want to be kept “full code” and that all medical interventions should be undertaken. The health practitioner can bring an application to the CCB to determine whether the SDM’s refusal to consent to a treatment or plan of treatment is done in furtherance of an expressed wish, or is in the patient’s best interests. If the SDM has not complied with his/her obligations, the CCB can order the SDM to consent to a treatment or plan of treatment.

In *M.A. v. Benes*, the Court of Appeal for Ontario explained the rationale for applications to determine whether the SDM is acting in accordance with the patient’s best interests:

Both A.M. and the Attorney General acknowledge that s.21(1) protects incapable persons by requiring their prior capable wishes to be respected both by the S.D.M. and by the Board.

But where an incapable person has not expressed a prior capable wish, deciding the appropriate treatment is far more complex. It is more complex because it is not known whether an incapable person would have consented to a particular treatment had that person been capable. Yet, respect for the dignity and welfare of an incapable person may require that person to be treated.

Sections 21 and 37 of the Act respond to this situation by requiring both the S.D.M. and the Board to apply a “best interests” test where an incapable person has not expressed a prior capable wish. Under s.37, the

Board considers the submissions of the S.D.M., the treating health practitioner, the incapable person and any other relevant party. The Board then decides whether the S.D.M. has applied s.21 properly. In other words, the Board, like the S.D.M., applies the criteria in s.21 and decides what is in the best interests of the incapable person. The Board can then direct the S.D.M. in accordance with its decision. Should the S.D.M. fail to comply with the Board's direction, decision making authority passes to the next ranking S.D.M. under s.20 of the Act.¹¹⁹

Similarly, in *Rasouli*, the Supreme Court of Canada explained the statutory scheme that has been developed to address conflicts between physicians and SDMs:

Where physicians and substitute decision-makers disagree about whether withdrawal of life support would be in the best interests of the patient, the *HCCA* provides the procedure for resolving this conflict. Under s. 37, the health care practitioner may apply to the Board to have the decision of the substitute decision-maker set aside on the ground that it is not in the best interests of the incapable person, having regard to the factors set out in s. 21(2) of the Act. This is an important avenue of recourse for physicians who believe that life support can no longer be ethically administered because it is not in the best interests of the patient to do so. The Board must duly consider the physician's professional opinion and submissions on what would be of medical benefit to the patient.

If the Board agrees that the substitute decision-maker did not act in the best interests of the patient, it may substitute its own opinion for that of the substitute decision-maker: s. 37(3). Alternatively, if the Board concludes that the substitute decision-maker did act in the best interests of the patient, it can affirm the decision of the substitute decision-maker. In making these determinations, the Board must objectively apply the same criteria that substitute decision-makers are required to consider under s. 21. The Board is well placed to make a determination of whether treatment is in the best interests of the patient, in light of the statutory objectives of enhancing patient autonomy and ensuring appropriate medical care....¹²⁰

As the Supreme Court noted, it is only where a physician and an SDM disagree, that the CCB will become involved to determine the best interests of the patient.

The facts of the case of *Grover v Grover* are illustrative of Form G applications.¹²¹ In that case, an appeal was brought before the Ontario Superior Court of Justice from a decision of the CCB ordering the withdrawal of life support. The health practitioner brought an application under section 37(1) to the CCB for a determination of whether the SDM had failed to comply with her obligations. Ms. Grover had been hospitalized after she suffered a stroke that left her in a state requiring life-support measures, including the use of a ventilator and an endotracheal tube. She had also suffered two prior strokes. The SDM, who was Ms. Grover's daughter, was acting on Ms. Grover's directive to do everything possible to save and prolong her life should she be in an "acute-care" situation. The CCB ordered the withdrawal of life support. In reaching this decision, the CCB concluded that the directive did not reflect Ms. Grover's capable wishes because she could not have foreseen the occurrence of a third stroke (as opposed to only two strokes). In the CCB's conclusion, Mrs. Grover's directive would have been different had she known that she would suffer a third stroke. This conclusion was upheld by the Superior Court of Justice.

(b) Applications by Incapable Patients or Third Parties

Even where a patient has been found incapable with respect to treatment and this finding has been upheld by the CCB, that patient is not helpless to challenge decisions made by a family member who is acting as his/her SDM. Under s. 33 of the *HCCA*, a patient (or another person) may apply to the CCB to have a different person appointed as the patient's representative. As the

representative, this new individual would rank above any other family member of the patient, and will only rank beneath a guardian of the person or attorney for personal care in the hierarchy of SDMs set out in s. 20 of the *HCCA*. The CCB will grant this appointment where it is in the patient's best interests.¹²² Patients may also apply to the CCB for a review of an SDM's decision to consent to the incapable patient's admission to a hospital for purposes of treatment, as contemplated under s. 24 of the *HCCA*.¹²³

(c) Other Applications by the SDM or Health Practitioner

SDMs and health practitioners may be put in unenviable positions. SDMs may be asked to interpret and apply vague, confusing or contradictory wishes. They may also be required by the *HCCA* to refuse treatment based on a prior capable wish when the patient, if capable today, may have given consent to the treatment. Similarly, health practitioners may be asked to comply with instructions given by SDMs in the above circumstances.

The *HCCA* recognizes the difficulties inherent in the role of the SDM applying prior capable wishes, and provides that an SDM or health practitioner may bring an application to the CCB where a wish expressed by the patient is unclear, and may also bring an application to depart from a prior capable wish. A typical case would be where the patient, while capable, expressed a wish to not receive a certain type of medication (e.g., neuroleptics); an SDM could apply to the CCB for permission to depart from the prior capable wish based on the fact that if the incapable patient knew at the time of making the wish what is now

known about reduced side effects to a particular medication, the patient may have made a different wish in the circumstances. In short, the CCB will give permission for the SDM to depart from a prior capable wish if it is satisfied that the patient, if capable, would probably give consent because the likely result of the treatment is significantly better than would have been anticipated in comparable circumstances at the time the wish was expressed.¹²⁴

Where the content of a wish, its applicability, or the capacity of the patient at the time the wish was expressed is unclear, the SDM or the health practitioner may apply to the CCB for directions on how to interpret and apply the wish.¹²⁵

D. Highlights of Consent and Capacity Law in Ontario

With the narrow exception of treatment in emergencies, informed consent must always be obtained from a patient (or if incapable, his/her SDM) before treatment is administered. Where the patient is capable, the law of Ontario limits the ability to consent to every possible prospective treatment. The patient can only lawfully give informed consent to treatments that relate to the patient's current health condition. Where a patient is incapable, an SDM is required to determine whether the patient has expressed applicable prior capable wishes (which must be followed by the SDM); or otherwise has expressed other wishes, values, and beliefs (which must be considered). The patient may express wishes, values and beliefs in any form, and recent expressions of prior capable wishes will prevail over older statements.

Importantly, with the narrow exception for emergencies, regardless of whether a patient is capable or not, or has expressed prior capable wishes or not, when a treatment is proposed informed consent must be obtained from a person. Even where an SDM has been found by the CCB to have not complied with his/her obligations, the CCB does not bypass the role of the SDM and order the health practitioner to either administer or withhold treatment. Instead, the *HCCA* provides that CCB will give “directions” to be followed by SDM in giving or refusing consent.¹²⁶

This legislative model balances the patient’s right to give informed consent to treatment with the patient’s right to give directions regarding future health care in the event he/she becomes incapable. The right to give or refuse informed consent entails being advised of the risks and benefits of a particular treatment as contextualized in the patient’s current health condition, and the health problems that a health practitioner has determined are likely to occur in future. The SDM’s role is to satisfy this right by speaking with health practitioners and making an informed decision based on the current information presented. However, as part of this consent process, the SDM is also required to situate the patient’s prior capable wishes in the context of the patient’s present health conditions, and give informed consent in accordance with these wishes where they are applicable.

IV. CONSENT AND ADVANCE CARE PLANNING

This section explores how advance care planning through instructional directives fits into the law of Ontario and concludes that (with the narrow exception of emergencies) patient wishes, values and beliefs can only be given effect by health practitioners through informed consent to treatment.

This section does not focus on advance care planning through the designation of a proxy decision-maker, as that subject is relatively clear in Ontario: patients can appoint an attorney pursuant to a power of attorney for personal care under the *SDA*.

A. Wishes, Values and Beliefs

One of the purposes of the *HCCA*, expressed in section 1(c)(iii), is “to enhance the autonomy of persons” by requiring that “wishes with respect to treatment, admission to a care facility or personal assistance services, expressed by persons while capable and after attaining 16 years of age, be adhered to.”¹²⁷

Rather than have a formalized mechanism for directly giving effect to advance care plans through health practitioners, the *HCCA* focuses on the role of the SDM giving informed consent to treatment and prescribes certain principles and guidelines that must be followed by the patient's SDM when making decisions on behalf of an incapable patient.¹²⁸ In providing these guidelines, the *HCCA* refers to the patient's expressed wishes, values and beliefs, and draws subtle distinctions between the legal effects of each.

The term “wishes” is not defined in the *HCCA*. Instead, the *HCCA* contains a clause broadening the scope of the phrase “wishes” beyond its use in common language, and providing some guidance on how multiple expressed wishes are to be prioritized:

Wishes

5. (1) A person may, while capable, express wishes with respect to treatment, admission to a care facility or a personal assistance service.

Manner of expression

(2) Wishes may be expressed in a power of attorney, in a form prescribed by the regulations, in any other written form, orally or in any other manner.

Later wishes prevail

(3) Later wishes expressed while capable prevail over earlier wishes.¹²⁹

While the *HCCA* permits the incorporation of a prescribed form for the expression of wishes by regulation, this has not been done.

As noted above, the genesis of both the *SDA* and the *HCCA* can be traced back to the Fram Report, which contained the following draft legislative clause related to patient wishes:

The Guardian [which for the purposes of this provision included an SDM for health-care] shall make decisions on the incapable person’s behalf in accordance with the intentions the person had before becoming incapable, and shall take into consideration the incapable person’s wishes, if those intentions and wishes can be ascertained.¹³⁰

Interestingly, the word “intentions” in the above quote did not survive into the equivalent provisions of the current legislation. Instead, the word “wishes” stands for both statements that must be *followed* by the SDM and statements that have to be *considered* by the SDM under the *HCCA*. In appearing before the Ontario

Standing Committee on Administration of Justice in 1991, Mr. Fram was asked about the term “wishes” and explained:

Mr Fram: We were searching around for a word. People in all of this medical literature have been searching around for a word. If you use the word "want," it is something connected with "will," and if you have "intentions" -- each of those terms gives rise to its own problems. The term "wish" is that form of instruction that can come up when people talk about their lives with each other. It is the conversation you have with your intimate friend when you say: "Gee, I've just watched Betty's grandmother deteriorate. If that happened to me, here's what I would want to happen and not happen."

It is an interesting word because it is that level of explanation of what we expect, we hope will happen to us if certain things take place. It is an interesting word, but it is the closest we have to that kind of concept of when we explain ourselves to our intimate friends.¹³¹

As set out in the above quote, “wishes” appears to have been left intentionally flexible and informal.

As previously noted, Ontario’s current legislation provides that wishes can be expressed in any form, including orally, and also provides that later expressed wishes will prevail over earlier expressed wishes. As such, a written document prepared with the help of a lawyer expressing capable applicable “wishes” can be nullified by any later applicable oral statements made by a patient while capable. For example, imagine a scenario where a patient has attended at his lawyer’s office to execute a power of attorney for personal care containing an instruction that he does not want CPR under any circumstances. If, after executing the power of attorney for personal care and on his way out the door, the patient orally states to the lawyer’s receptionist “but I do want to be resuscitated if I experience a cardiac or respiratory arrest during surgery”, this latter oral wish will trump the

earlier formally expressed instruction in the power of attorney for personal care – but only with respect to resuscitation during surgery. As will be seen below, this is a commonly misunderstood aspect of Ontario’s legislative scheme, with the result that health practitioners are sometimes biased towards the written word when a document is in conflict with oral statements later recounted by an SDM or other witness

In Ontario, where the patient has expressed “wishes” when capable that are “applicable to the circumstances”, the SDM is required to act in accordance with those wishes (subject to an application to the CCB to depart from those wishes, discussed above).¹³² Where applicable wishes were expressed at a time when the patient was incapable, or where those expressed wishes are not “applicable to the circumstances” yet are “with respect to the treatment”, they must be considered by the SDM in determining the incapable patient’s best interests.

The *HCCA* draws a distinction between expressed “wishes” and the “values and beliefs” the patient held when capable and that the SDM believes the patient would still act on if capable. There is no definition of “values and beliefs” in the *HCCA*, and there is no statutory guidance on how these values and beliefs are to be interpreted – except that the SDM must believe that the patient would still act on them. There is similarly no standard system for recording or documenting values and beliefs under the *HCCA*. The *HCCA* requires that the

SDM consider the patient's values and beliefs as part of determining the patient's best interests.

B. The Substitute Decision-Maker as Interpreter

Under the *HCCA*, prior expressed wishes, and the values and beliefs of the patient, are not directly acted upon by the patient's health care team (with the exception of emergencies). Rather, the SDM serves as an interpreter, responsible for determining if prior wishes expressed by the patient are "applicable in the circumstances" (and must be followed) or merely were expressed "with respect to the treatment" (and must be considered along with values and beliefs and other factors as part of determining whether the proposed treatment is in the incapable patient's best interest). Absent an application to the CCB by a health practitioner to determine if the SDM is complying with his/her obligations under s. 37 of the *HCCA*, or an application by the SDM for directions, the SDM is the legal interpreter of the effect of prior statements made by the patient - this includes interpreting whether the patient was capable at the time the statement was made, and whether these statements are expressions of wishes or reflect the values and beliefs held by the patient.

This is not to say that health practitioners should blindly accept decisions made by SDMs. To borrow an example from our health practitioner consultations, one health practitioner recounted an incident where an SDM claimed that a persistently unconscious patient suddenly sat up in bed and experienced a lucid and capable moment during which he expressed wishes applicable to future

health care. The SDM recounted that the patient then returned to his previous state without anyone else witnessing this event. The health practitioner explained that from a clinical perspective, the occurrence of such a moment of lucidity was extremely unlikely. In the opinion of the authors, this health practitioner was not obliged to blindly follow a decision of the SDM based on this questionably expressed wish. Health practitioners still have an important role in considering whether the SDM is complying with his/her obligations, and deciding whether to bring a Form G application under s. 37 of the *HCCA*.

Importantly, the SDM cannot express new wishes, values or beliefs on behalf of the incapable patient and as such, cannot advance care plan on behalf of the patient. The SDM can only interpret and apply expressions of wishes and the patient's values and beliefs in giving or refusing consent to treatment or a plan of treatment on behalf of the incapable patient. SDMs may also recount prior capable wishes expressed by the patient to health practitioners, which can be relied upon by health practitioners in providing or withholding treatment to an incapable patient in an emergency. SDMs have no other authority to control or restrict treatment provided to the patient under the *HCCA*, and most certainly cannot do so based on their own wishes or preferences. As will be seen below, the role of the SDM is construed quite differently in Ontario, in contrast to the law of other Canadian and international jurisdictions.

The Fram Report proposed that, with the exception of emergencies, prior expressed statements by patients would be acted upon and interpreted by the

patient's SDM, and not the patient's health practitioners. The Fram Report apparently considered and rejected the option of having physicians make decisions on behalf of patients, except in emergencies. In the words of the Committee:

The central policy issue that the Committee has addressed in considering substitute consent to medical and psychiatric treatment is whether it is better to provide for a near relative to consent to treatment for a person whom a physician believes is incapable of giving consent, or to provide that only emergency treatment be given without the consent of a court appointed guardian. The Committee considered and rejected the option of dispensing with consent for treatment of a mentally incapable person when two or more physicians provide a written opinion that the treatment is needed and therapeutic. The providers of services should not be asked to determine the value of their services to the life of an individual.

In coming to a decision, the Committee considered the issue from a number of perspectives. It considered the question of intrusiveness. Consent given by a near relative under a statute would be less disruptive to an individual's life and less intrusive than a court application...¹³³
[Emphasis added]

The Fram Report recommended that health practitioners should not be asked to make decisions about the value of treatment to the life of their patients. Instead, this is left to SDMs who most often, based on the hierarchy of ranked SDMs in s. 20 of the *HCCA*, will be close family members of the patient.

Interestingly, the Fram Report also recommended that, to ensure authenticity of a decision, default family member SDMs should certify that they have been in "friendly personal contact with the patient over the preceding twelve-month period."¹³⁴ This latter suggestion did not survive into the current legislation. Furthermore, the argument that decisions of SDMs should be entitled to deference as a result of their close personal relationship with the patient was rejected by the Court of Appeal in *M.A. v. Benes*:

...although sometimes an S.D.M. will know better than the Board about an incapable person's beliefs, values and previous non-binding wishes, that will not always be so. Not all family members are close, and even when they are close, they do not always know what treatment the incapable person would want. Even so, the Act respects the values, beliefs and previous nonbinding wishes of the incapable person that are known to the S.D.M. The S.D.M., not the treating health care practitioner or the Board, makes the initial treatment decision. The Board, though it may substitute its opinion for that of the S.D.M., must nonetheless take into account the S.D.M.'s submissions on the incapable person's values, beliefs and non-binding wishes because these criteria are part of the best interest test under s.21(2) of the Act and the Board must apply s.21(2).¹³⁵

Even without deference, the SDM remains the decision-maker at first instance for the incapable patient.

C. The Emergency Exception

As noted above, there is an important exception to the statement that the incapable patient's wishes, values and beliefs can only be acted upon through the SDM's consent to treatment or a plan of treatment. In an emergency, health practitioners are not required to obtain consent before providing treatment to a patient. The *HCCA* distinguishes between emergencies involving capable and incapable patients, and provides that health practitioners may proceed directly to treatment where a patient is either:

- (a) capable but unable to communicate with the health practitioner; or,
- (b) incapable and the SDM cannot be reached in time.

The *HCCA* is careful to not designate patients who are unable to communicate (for example, due to the absence of a translator) as incapable. Such patients remain capable, but may still be treated in an emergency while a means of communication is being found.

In emergencies, health practitioners are legally obliged to consider and interpret prior capable wishes expressed by the patient. Specifically, health practitioners may not administer treatment if they have reasonable grounds to believe that a patient expressed a capable wish to refuse the treatment. In the case of a capable patient, there is an additional requirement: the health practitioner cannot provide treatment if there is a reason to believe the person does not want the treatment. This additional, and broader, basis for not administering treatment to capable patients may be aimed at addressing the fact that SDMs have no authority to make treatment decisions where a patient is capable but unable to communicate. Where the patient is capable but unable to communicate, someone other than the patient may provide the health practitioner with a reason to believe the person does not want the treatment.

Where an SDM can be reached in time and refuses to consent to treatment for an incapable patient in an emergency, the health practitioner can disregard this refusal where he/she is of the opinion the SDM has not complied with his/her obligations under the *HCCA*.¹³⁶

The emergency exception is not as broad as it seems. It only applies if the person for whom the treatment is proposed is apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm. Once a reasonable amount of time has elapsed to find a way for a capable patient to communicate, or a reasonable amount of time has

elapsed to allow informed consent or refusal from an incapable patient's SDM, this exception no longer applies.

D. Consent to Plan of Treatment

While an SDM may not express new wishes, values and beliefs on behalf of the patient, this does not mean that an SDM cannot play an active role in guiding future care for an incapable patient. The *HCCA* provides that consent may be given to future treatments, not contemporaneously proposed for the patient, as part of providing consent to a plan of treatment. As discussed above, a plan of treatment is defined as follows under the *HCCA*:

“plan of treatment” means a plan that,

(a) is developed by one or more health practitioners,

(b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and

(c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition; (“plan de traitement”)

...

Plan of treatment

13. If a plan of treatment is to be proposed for a person, one health practitioner may, on behalf of all the health practitioners involved in the plan of treatment,

(a) propose the plan of treatment;

(b) determine the person's capacity with respect to the treatments referred to in the plan of treatment; and

(c) obtain a consent or refusal of consent in accordance with this Act,

(i) from the person, concerning the treatments with respect to which the person is found to be capable, and

(ii) from the person's substitute decision-maker, concerning the treatments with respect to which the person is found to be incapable.¹³⁷

In order to give or refuse consent to future treatments that are not yet proposed for the patient by the health practitioner, the plan of treatment must relate to the patient's "current health condition." Consent to a plan of treatment must still be informed, with the health practitioner discussing the "matters" specified in the *HCCA*:

1. The nature of the treatment.
2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.¹³⁸

To obtain informed consent, the SDM must be aware of the risks and benefits of treatment, which requires an appreciation of the patient's clinical picture at the time these treatments are to be administered. Furthermore, these proposed treatments must relate to the health problems that the patient is likely to have in the future given the patient's current health condition.

Over time, as the risks and benefits of treatment significantly change based on the progression of the patient's current health condition, or where the patient has developed health problems that were not likely at the time the plan of

treatment was consented to and that require treatment, the health practitioner is required to return to the SDM (or the patient if capable) to obtain consent.

E. The Caselaw

When faced with evidence of advance care planning, courts and administrative decision-makers have embarked on an analysis of whether these advance care plans are properly wishes “applicable to the circumstances”, wishes “with respect to treatment”, or “values and beliefs”.

The difference between wishes that must be followed by the SDM and other wishes, values and beliefs that must be considered by the SDM turns on the degree of specificity expressed by the patient. In *Scardoni v Hawryluck*¹³⁹, the Ontario Superior Court stated that:

For the purpose of consent to treatment, the interests of a patient's individual autonomy are reflected in s. 21(1)1. Where the wishes of the patient are not known with sufficient exactness to satisfy the requirements of that provision, they may still be given weight under paras. (a) and (b) of s. 21(2) in determining the patient's best interests. [Emphasis added]¹⁴⁰

Similarly, in *Rasouli*, the majority of the Supreme Court noted that:

...a prior wish will only be binding if it is applicable to the patient's current circumstances. Vagueness in a prior wish or changes in the patient's condition, prognosis, or treatment options may mean that the prior wish is inapplicable. Where prior wishes are inapplicable, the best interests analysis governs.¹⁴¹

The case of *M.B. (Re)* is a good example of the distinction between “wishes” and “values and beliefs”. In that case, the patient expressed a wish to die by taking his dog into the mountains for the winter and not coming back. The CCB found that this wish was too general (and impractical) to be a mandatory direction. However, the CCB found that this statement reflected the patient's

values and beliefs about his end-of-life preferences, and therefore must be considered as part of determining the patient's best interests.¹⁴²

The seminal decision of the CCB on whether prior capable wishes are “applicable to the circumstances,” is *M.F. (Re)*. That case dealt with the provisions in the *HCCA* relating to consent to admission on an incapable person's behalf to a care facility. Ms. M.F. had previously executed a power of attorney for personal care stating that she wanted to stay in her home. However, at the date of the hearing, Ms. M.F. now required constant supervision and help with her activities of daily living. The CCB was asked to interpret Ms. M.F.'s expressed wish to stay in her home, to determine whether this wish was “applicable to the circumstances”, and wrote the below off-cited passage:

Other than that it must be capable, what is the nature of wish the legislation contemplates? According to s. 42 (1), it is a wish “applicable to the circumstances.” Put differently, the wish needs either enough specificity to relate to the person's situation at the time of the Hearing or enough breadth to be applicable to the proposed treatment or admission regardless of the circumstances.

Generally, there are three types of wishes one might express regarding a treatment or care decision. The first arises out of deeply held beliefs, such as the wish of a Jehovah's Witness not to receive a blood transfusion. The second responds to an imminent extenuating circumstance, such as major and risky surgery. The third category is a general expression of sentiment in contemplation of an uncertain future.

In the first category, the beliefs underlying the wish are likely to be concrete and therefore precise. There is likely certainty to the wish and its applicability to the circumstances however far in advance it was made: “Under no circumstances give me a blood transfusion.”

In the second category, the person expressing the wish is anticipating what the near future holds. In the case of major surgery, a person will have the benefit of medical advice including an assessment of the risks and range of outcomes. The time frames are constrained. Considerations other than the risks and results of the procedure, such as family and

finances, are predictable in the short term, before the vagaries of life have much time to interfere in plans. The instruction given to a substitute decision-maker is based upon that current information. Such a wish is therefore likely to be made with certainty and with realistic application to the person's circumstances.

In the third category, the person expressing the wish anticipates something that, if it does transpire, will take place in the indeterminate future. Surrounding circumstances may change from the time the wish is expressed to the time it might be applicable. Life can be unpredictable.

In the first two cases, the wish and the circumstances to which it applies are concrete. In the third situation, fate might foil the best laid plans. The legislation qualifies the obligation of a substitute decision-maker to give effect to advance directives by requiring that the wish be applicable to the circumstances. The wish needs a framework of relevance to the time it might be implemented.

It would be impossible for someone sitting in a lawyer's office about to execute a Power of Attorney for personal care to anticipate every contingency of future needs. I think it likely that many expressions, many wishes made at that time, are more intended as philosophical guidelines for the attorney than hard and fast directions to be followed no matter what. Consequently, I am sceptical about the extent to which comments of a general nature addressing unforeseeable contingencies are intended by the legislation to be wishes mandated for slavish adherence. Such general outlines of preference may, as life unfolds, not be applicable to the circumstances.¹⁴³

In that case, the CCB concluded that Ms. M.F.'s prior capable wish was not applicable to the circumstances as her expressed wish was "too vague and her circumstances too likely not within what she was contemplating when she said what she did to be applicable."¹⁴⁴ Alternatively, even if the wish was applicable, the CCB would have interpreted a caveat into Ms. M.F.'s prior statement that she wished to stay in her home "as long as I am able to manage there with whatever help is available."¹⁴⁵

As the above quote in *M.F.* demonstrates, the CCB will take a hard look at any expressed prior capable wish, or the purported values and beliefs of the

incapable patient that would result in significant pain or diminished dignity to the patient if followed by the SDM. The CCB tends to be skeptical of a patient's ability to foresee the unfortunate clinical situations that may befall the patient in the future.

The consideration of values and beliefs of the patient sometimes involves an abstract examination of the patient's ideological or faith community. The case of *S.S. (Re)* is a notable example. In that case, the SDM was the daughter of the patient, and she refused to consent to a treatment plan involving a discontinuation of active care proposed by the patient's physicians. The SDM gave evidence that consenting to a discontinuation of active care would be contrary to the Islamic faith, in which the patient was a believer. Interestingly, a physician practicing in the patient's palliative care group also practiced the Islamic faith and gave evidence that "there is nothing in the Islamic Law which prevented changing treatment when it was deemed appropriate" and that "if treatment was not beneficial to the patient and was only prolonging the inevitable, that it would be appropriate to stop or change that treatment."¹⁴⁶ Faced with this lay debate on the tenets of the Islamic faith, the CCB held that the thinking of the SDM was "flawed because that was not the Islamic belief". The CCB also relied upon the fact that the SDM had not discussed these beliefs with her mother.¹⁴⁷

Deciding between multiple vague and conflicting statements made by a patient can be a difficult task. Sometimes, actions speak louder than words. In *M.*

(*Re*), Ms. M. had executed a “living will” stating that “If I have to go into a nursing home or a place that gives ongoing care, I wish to stay in the Kitchener-Waterloo area.” Ms. M later informed her family that she wished to live in her home until she died. Later still, Ms. M took steps to move herself into a long-term care home. At the hearing, one of Ms. M’s daughters presented an unsigned and undated document entitled “Advance Care Planning for [M] Report”, putting forward a plan of care that Ms. M would move into a long-term care home when she reached 99 years of age (Ms. M. was 98 at the time of the CCB hearing). As the Advance Care Planning Report was unsigned and referred to Ms. M in the third person, it was not considered to be a prior capable wish. The CCB found that Ms. M’s prior capable wish was expressed in her decision to place herself on the waitlist for long-term care, and concluded that Ms. M. should be admitted to a long-term care facility.¹⁴⁸

However, even when presented with a signed document expressing a wish on behalf of the patient, the CCB cannot unreasonably accept that this document contains the true prior capable wishes of the patient. In *Barbulov v. Cirone*, the patient had executed a power of attorney for personal care many years in the past. The CCB found that the wishes expressed in this document were binding on the SDM. This decision was overturned by Brown J. on appeal to the Superior Court of Justice, who noted that the evidence before the CCB was that Mr. Barbulov did not read the document, had limited command of written English, and did not have the document translated to him. Brown J. held that it

was unreasonable for the CCB to rely upon this document as expressing the prior capable wishes of the patient, and rejected a contractual approach for the interpretation of powers of attorney for personal care.¹⁴⁹

In summary, advance care planning encompasses a myriad of statements and documents with differing legal effects. Under Ontario law, all wishes, values, and beliefs expressed as part of advance care planning must be analyzed to determine whether they are sufficiently specific to be “wishes” or are merely the patient’s “values and beliefs”. If “wishes”, the patient’s current clinical picture must be carefully considered by the SDM to determine if these “wishes” are “applicable to the circumstances” (and must be followed) or are merely “with respect to the treatment” (and must be considered along with the patient’s values and beliefs).

There is, or appears to be, a general reluctance (understandably) on the part of the CCB and the courts to find that a patient’s true intention was to live in pain and/or with undignified and ineffective medical interventions. When involved in advance care planning, patients should recognize that from a practical perspective, only the most deeply held, clearly stated, and categorically expressed wishes will be binding on an SDM if the patient intends to be kept alive in all circumstances. As the majority of the Supreme Court of Canada stated in *Rasouli*, referring to prior expressed wishes that were not “applicable”:

...although a patient’s beliefs and prior expressed wishes are mandatory considerations, there is no doubt that the medical implications of a proposed treatment will bear significant weight in the analysis.¹⁵⁰

V. HEALTH CARE CONSENT AND ADVANCE CARE PLANNING: A NATIONAL AND INTERNATIONAL REVIEW

A. Introduction

This section provides a national and international overview of the laws and structures governing health care consent and advance care planning outside Ontario. Within Canada, we examined four provinces: British Columbia, Alberta, Nova Scotia and Saskatchewan. Outside Canada, we studied England, Queensland (Australia), Hawaii (USA), Oregon (USA), and Texas (USA). We chose these jurisdictions for a variety of reasons, including: language (these jurisdictions speak and write in English, and their statutes are readily available in English); similar legal systems; and varying size (in terms of both geography and population). We were also aware that some of the jurisdictions we reviewed had noteworthy laws and/or approaches to health care consent. As examples, we knew that British Columbia had a unique model in which an advance directive was equivalent to consent, that Hawaii provided an example of a state that had adopted the model Uniform Health Care Decisions Act, and that England gave a great deal of authority to health practitioners to make treatment decisions for incapable patients.

The purpose of the comparative literature review was to analyze different legal models to explore how they differ from the laws of Ontario, to determine if foreign legislation could offer possible reforms for Ontario, and to consider how these models may contribute to persistent misunderstanding of Ontario's health care consent and advance care planning laws.

It is beyond the scope of this Paper to provide an exhaustive review and analysis of the laws and practices of these jurisdictions. We have not summarized all aspects of the law of health care consent and substitute decision-making in these jurisdictions to avoid unnecessary detail and length. As a notable example, we have not summarized the law of emergency treatment in each jurisdiction, as this is not the focus of our analysis in Ontario. Furthermore, we acknowledge that there may well be gaps between what is outlined in legislation and what happens in practice in other jurisdictions, as is the acknowledged experience in Ontario.

For ease of comparison, our explication of the law of each other jurisdiction is summarized under the following headings:

1. Is there a statutory provision setting out the requirement to obtain informed consent?
2. Is there a statutory mechanism for creating an advance directive?
3. What is the legal effect of an advance directive?
4. Who interprets and applies the advance directive?
5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?
6. Who makes decisions for an incapable patient who has not appointed a proxy?
7. How are disputes resolved?

As set out below, many jurisdictions address the relationship between advance care planning and health care consent through an analytical and legal framework

that can be contrasted to that of Ontario. In all of the jurisdictions we reviewed, there is a general requirement to obtain informed consent before treatment is administered.

B. British Columbia

1. Is there a statutory provision setting out the requirement to obtain informed consent?

The British Columbia *Health Care (Consent) and Care Facility (Admission) Act* generally requires that consent be obtained before treatment is administered, and presumes that patients will be capable¹⁵¹ of giving, refusing, or revoking 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.¹⁵²

The British Columbia legislation also requires that, before attempting to obtain consent from an SDM or providing treatment in an emergency, the health practitioner must make every reasonable effort to obtain a decision from the adult.¹⁵³

As in Ontario, the British Columbia legislation prescribes that consent must relate to the particular health care proposed to the patient, and sets out the information that health care providers must provide to patients in order for that consent to be lawful:

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.¹⁵⁴

2. Is there a statutory mechanism for creating an advance directive?

While many of the provisions regarding consent to treatment in the *Health Care (Consent) and Care Facility (Admission) Act* are similar to the provisions of the *HCCA*, one important difference is that in British Columbia, an “Advance

Directive” is a formal legal document. The British Columbia statute specifically provides a mechanism for patients to give directions about future health care, and requires that these directives be in writing.¹⁵⁵

Interestingly, the *Health Care (Consent) and Care Facility (Admission) Act* does not contain a provision permitting an adult to appoint a proxy decision-maker as part of creating an advance directive. Instead, patient appointed proxy decision-making in British Columbia is dealt with under the *Representation Agreement Act*.¹⁵⁶ Under the *Representation Agreement Act*, an individual may appoint a representative to make, or help the individual make, decisions in the event he/she becomes incapable of making decisions independently.¹⁵⁷ Depending on the terms of the representation agreement, the representative may also make all health care decisions for the individual under the *Health Care (Consent) and Care Facility (Admission) Act* if the individual is incapable.¹⁵⁸ The *Representation Agreement Act* also allows individuals to appoint monitors to determine whether representatives are complying with their health care decision-making obligations (monitors are mandatory for representatives handling finances).¹⁵⁹

In making, or helping the patient to make, health care decisions, the *Representation Agreement Act* provides:

16 (1) A representative must

- (a) act honestly and in good faith,
- (b) exercise the care, diligence and skill of a reasonably prudent person, and

(c) act within the authority given in the representation agreement.

(2) When helping the adult to make decisions or when making decisions on behalf of the adult, a representative must

(a) consult, to the extent reasonable, with the adult to determine his or her current wishes, and

(b) comply with those wishes if it is reasonable to do so.

(2.1) Subsection (2) does not apply if

(a) a representative is acting within authority given to the representative under section 9 [a section providing for some of the powers that may be given to a representative], and

(b) the representation agreement provides that in exercising that authority the representative need only comply with any instructions or wishes the adult expressed while capable.

(3) If subsection (2) applies but the adult's current wishes cannot be determined or it is not reasonable to comply with them, the representative must comply with any instructions or wishes the adult expressed while capable.

(4) If the adult's instructions or expressed wishes are not known, the representative must act

(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.¹⁶⁰

Where a patient has both an advance directive under the *Health Care (Consent) and Care Facility (Admission) Act* and has appointed a representative with authority to make health care decisions under the *Representation Agreement Act*, the statements expressed in the advance directive are treated as “wishes of the adult, expressed while capable” to be considered by the representative, unless the patient has stipulated in the representation agreement that the health

care provider may comply with the advance directive without consent from the representative.¹⁶¹

Interestingly, under the *Representation Agreement Act*, even where an advance directive is treated as prior capable wishes, the representative will still have an obligation to:

(a) consult, to the extent reasonable, with the adult to determine his or her current wishes, and

(b) comply with those wishes if it is reasonable to do so.¹⁶²

Current incapable wishes will trump prior capable wishes where it is reasonable to do so, unless the representation agreement provides that the representative need only comply with capable wishes.¹⁶³ We should note that a representation agreement may be drafted with more limited authority, with the result that an advance directive will continue to apply.

The *Representation Agreement Act* incorporates the test for best interests under the *Health Care (Consent) and Care Facility (Admission) Act* for health care decisions made by representatives.¹⁶⁴

3. What is the legal effect of an advance directive?

Under British Columbia law, an advance directive under the *Health Care (Consent) and Care Facility (Admission) Act* is equivalent to consent to treatment and may be acted upon directly by a health care provider without consultation with an SDM:

Providing health care if adult has advance directive

19.7 (1) Subject to section 19.8, this section applies when

(a) in the opinion of a health care provider, an adult needs health care,

(b) the adult is incapable of giving or refusing consent to the health care, and

(c) the health care provider

(i) does not know of any personal guardian or representative who has authority to make decisions for the adult in respect of the proposed health care, and

(ii) is aware that the adult has an advance directive that is relevant to the proposed health care.

(2) A health care provider

(a) may provide health care to an adult if the adult has given consent to that health care in the adult's advance directive, and

(b) must not provide health care to an adult if the adult has refused consent to that health care in the adult's advance directive.

(3) A health care provider is not required to make more than a reasonable effort in the circumstances to determine whether the adult has an advance directive or a personal guardian or representative.¹⁶⁵ [Emphasis added]

The British Columbia legislation specifically exempts consents given via an advance directive from the requirement that consent to treatment be informed, so long as the adult is capable of giving the advance directive.¹⁶⁶ As such, an individual may consent to treatment without discussing it with a health practitioner, or indeed without having any knowledge of the risks and benefits of the treatment. In this respect, British Columbia has resolved the tension between informed consent and advance directives differently than Ontario: it has removed the requirement that consent be informed.

4. Who interprets and applies the advance directive?

Where there is a concern regarding the applicability of an advance directive, the task of interpreting the advance directive is given to the health practitioner – as opposed to an SDM as is the case in Ontario.¹⁶⁷ This is a function of the fact that, in British Columbia, an advance directive is a form of consent to treatment. Of course, if a representative has authority over the decision under a representation agreement, that representative is responsible for interpreting the advance directive as prior capable wishes, as set out above.

British Columbia legislation provides that a health practitioner may refuse to comply with an advance directive if he/she reasonably believes that:

- (a) the instructions in an adult's advance directive do not address the health care decision to be made,
- (b) in relation to a health care decision, the instructions in an adult's advance directive are so unclear that it cannot be determined whether the adult has given or refused consent to the health care,
- (c) since the advance directive was made and while the adult was capable, the adult's wishes, values or beliefs in relation to a health care decision significantly changed, and the change is not reflected in the advance directive, or
- (d) since the advance directive was made, there have been significant changes in medical knowledge, practice or technology that might substantially benefit the adult in relation to health care for which the adult has given or refused consent in an advance directive.¹⁶⁸

Where an advance directive is not followed, the health practitioner is required to seek informed consent from the SDM.¹⁶⁹ Importantly, a patient may specify that an advance directive will continue to apply regardless of any changes in medical knowledge, practice, or technology – thereby nullifying the effect of (d) in the above quote.¹⁷⁰

5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

British Columbia law draws a distinction between the effect of an advance directive and other informal expressions of wishes, values, and beliefs. As noted above, in British Columbia an advance directive is a document that “gives or refuses consent to health care.”¹⁷¹ As such, an advance directive may be relied upon directly by a health care provider.

Informal wishes, expressed by the patient, cannot be directly implemented by the health care provider and, similar to Ontario, must be interpreted by the SDM. An SDM is still required to comply with capable wishes, to consider the patient’s values and beliefs, and also to act in the patient’s best interests (similar to the law in Ontario).¹⁷² However, unlike the effect of instructions, wishes, values, and beliefs of the patient, an advance directive is a formal document with a distinct legal effect: consent to treatment.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

Where a decision cannot be obtained from the adult, the *Health Care (Consent) and Care Facility (Admission) Act* contains provisions authorizing consent to health care by a temporary SDM as selected by a hierarchy similar to that contained in s. 20 of the *HCCA*.¹⁷³ As noted above, the temporary SDM must comply with any prior capable instructions expressed by the patient. If there are no such instructions, the SDM must consider the patient’s current wishes, as well as his/her known beliefs and values.¹⁷⁴

7. How are disputes resolved?

Where there is a dispute pertaining to an advance directive, the *Health Care (Consent) and Care Facility (Admission) Act* allows a health care provider, a representative, personal guardian, person chosen under that act to give or refuse consent, and the incapable person to bring a court application for directions.¹⁷⁵ Unlike in Ontario, British Columbia has not created a specialized quasi-judicial board to hear and decide disputes relating to substitute decision-making.

The *Representation Agreement Act* allows for investigations by the British Columbia Public Guardian and Trustee, which may then bring an application to Court for an order, *inter alia*, confirming a change to, or the revocation of, a representation agreement, or for an order cancelling all or part of a representation agreement. The Court may also give advice and directions concerning the interpretation of a representation agreement.¹⁷⁶

8. Summary and Commentary

In summary, the British Columbia legislation permits patients to make health care decisions for future treatment that have not yet been proposed by treating physicians. Advance directives are not treated as expression of wishes, values, and beliefs. Instead, they are viewed as decisions to consent to, or refuse, treatment, which may be acted upon directly by a health practitioner (provided they are applicable, etc).

British Columbia provides an example of a jurisdiction that has prioritized patient autonomy to direct future treatment over the patient's right to give or refuse informed consent to treatment. This is a policy decision that has notable practical advantages. Allowing patients to pre-consent or refuse treatments (without requiring that those consents be informed), is a rule that is easy to follow for health practitioners. This rule also likely saves time and effort that would otherwise be spent by health practitioners locating and informing SDMs of the patient's present condition and his/her wishes. Where a patient has given an advance directive, British Columbia health practitioners may simply comply with the directive if they believe it is applicable.

The drawback of this legislative model is that patients may be inadvertently constrained by uninformed and inapplicable wishes. As recognized by the Fram Report (above), SDMs (who are usually close family members or are chosen by the patient) are in a unique position to ensure that decisions are authentic. Patients are unlikely to know their future clinical picture (at the time when the advance directive is relied upon by the SDM) at the time they give the advance directive. Health practitioners will likely have only passing contact with a patient, and not know the patient's actual understanding of the treatments pre-selected or refused or the assumptions that underlie the advance directive. What this legislative model creates in certainty, it loses in inflexibility.

C. Alberta

1. *Is there a statutory provision setting out the requirement to obtain informed consent?*

In Alberta, there is no statute that codifies the requirement to obtain informed consent. Instead, the common law of informed consent to treatment continues to apply in Alberta.

2. *Is there a statutory mechanism for creating an advance directive?*

In Alberta, the *Personal Directives Act* provides that Albertans have the right to give advance personal instructions regarding their own personal matters, which are defined as follows:¹⁷⁷

“Personal matters” include any matter of a non-financial nature such as health care; accommodation; with whom the person may live and associate; participation in social, educational and employment activities; and legal matters.¹⁷⁸

Under that *Act*, legal effect is given only to instructions that are given in writing and comply with the requirements prescribed by the *Act*.¹⁷⁹ The grantor of a personal directive is referred to as a “maker”. The grantor may also appoint an “agent” to make health care decisions in a personal directive. The decision-making authority granted to an agent by way of a personal directive is for all personal decisions on all personal matters unless stated otherwise in the directive.¹⁸⁰

Similar to the British Columbia *Representation Agreement Act*, the Alberta *Adult Guardianship and Trustee Act*¹⁸¹ allows individuals to appoint supporters, through a supported decision-making authorization, to assist that individual with,

inter alia, health care decisions.¹⁸² A decision made with the assistance of the supporter is “the decision of the supported adult for all purposes”, unless there is undue influence, fraud, or misrepresentation.¹⁸³

3. *What is the legal effect of an advance directive?*

The *Personal Directives Act* does not contain a provision equating advance directives with informed consent to treatment, or stating that instructions in a personal directive have the same effect as a decision made by the patient when capable (as in other jurisdictions). The effect of a personal directive is a function of its interpretation by agents and service providers, set out below.

4. *Who interprets and applies the advance directive?*

In Alberta, a personal directive is interpreted by an agent, unless the directive does not appoint an agent, or that agent is not available. In those latter circumstances, a personal directive is interpreted by a treating service provider.

The *Personal Directives Act* stipulates that an agent must follow any clear instructions provided in the personal directive that are relevant to the personal decision to be made.¹⁸⁴ If there are no clear instructions that are relevant to the decision, the agent is required to make the decision that the agent believes the maker would have made in the circumstances, based on the agent’s knowledge of the maker’s wishes, beliefs and values. If the agent does not know the maker’s wishes, beliefs and values, he or she must make the decision that is in the best interest of the maker.¹⁸⁵ This is an interesting analytical difference with the

Ontario *HCCA*, where wishes, beliefs and values are considered as part of determining the patient's best interests.

The *Personal Directives Act* also sets out the responsibilities of "service providers" (which would include health practitioners) in relation to personal directives. When providing personal services to a person who lacks capacity:

1. If an agent is designated in the personal directive:

The service provider must follow the relevant instruction of the agent.¹⁸⁶ When a person claims to be an agent, the service provider has a duty to satisfy himself or herself of the identity of the claimed agent, and of the authority of the claimed agent to make personal decisions.¹⁸⁷

2. If no agent is designated in the personal directive or the designated agent is unwilling or unable or cannot be contacted after every reasonable effort made:

The service provider must follow any relevant clear instruction in the personal directive.¹⁸⁸

3. If no agent is designated in the personal directive and there are no relevant, clear instructions in the personal directive, or a designated agent cannot be contacted after every reasonable effort has been made or is unable or willing to make the decision:

The service provider must make every reasonable effort to contact the maker's nearest relative for the purposes of informing him or her about the circumstances.¹⁸⁹

Where no agent is designated, a relevant and clear personal directive will speak directly to the health practitioner in deciding whether to provide treatment to the patient. Otherwise, the personal directive will be interpreted by the agent.

5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values, and beliefs?

The Alberta *Personal Directives Act* draws a distinction between formal written advance directives contained in a personal directive, and other expressions of wishes, values and beliefs by the patient. Specifically, the *Act* provides:

14...(2) An agent must follow any clear instructions provided in the personal directive that are relevant to the personal decision to be made.

(3) If the personal directive does not contain clear instructions that are relevant to the decision to be made, the agent must

(a) make the decision that the agent believes the maker would have made in the circumstances, based on the agent's knowledge of the wishes, beliefs and values of the maker, or

(b) if the agent does not know what the maker's wishes, beliefs and values are, make the decision that the agent believes in the circumstances is in the best interests of the maker.¹⁹⁰

The agent must follow any clear instructions in the personal directive, but where there are no such clear instructions the agent must either make the decision the agent believes the patient would make based on the patient's expressed wishes, beliefs, and values or if there are not such expressed wishes, beliefs, and values make a decision in the patient's best interests.

As noted above, the *Personal Directives Act* also draws a distinction between personal directives and informally expressed wishes in the obligations placed on service providers. Specifically, the *Act* requires that service providers follow clear instructions in a personal directive where no agent is appointed or the agent is unavailable. The *Act* does not require that service providers comply

with, or even consider, other informally expressed wishes, values and beliefs in similar circumstances.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

Where no personal directive has been made, the default provisions regarding consent to treatment on behalf of incapable persons apply under the *Alberta Adult Guardianship and Trustee Act*.¹⁹¹ Under that *Act*, a health practitioner may select a “specific decision-maker” to make a decision respecting the adult’s health care, or the adult’s temporary admission to or discharge from a residential facility. However, the health practitioner may not appoint a specific decision-maker for a decision for which a personal directive has been made.¹⁹²

As in Ontario, the health practitioner is required to “select” the default decision-maker from a hierarchy.¹⁹³ Interestingly, absent a personal directive, the specific decision-maker is not statutorily required to comply with a prior applicable wish expressed by the patient. Rather the specific decision-maker is required to act in the patient’s best interest and consider “any wishes known to have been expressed by the adult while the adult had capacity” and “any values and beliefs known to have been held by the adult while the adult had capacity.”¹⁹⁴ In this way, Alberta legislation again draws a distinction between the effect of a personal directive and other informally expressed wishes, values, and beliefs of the patient.

7. How are disputes resolved?

The *Personal Directives Act* and the *Adult Guardianship and Trustee Act* both allow for court applications to resolve disputes regarding substitute decision-making (or the operation of an advance directive).¹⁹⁵ The *Personal Directives Act* allows for complaints to, and investigations by, the Alberta office of the public guardian and trustee.¹⁹⁶

8. Summary and Commentary

Alberta's legislation permits a patient to create a written personal directive that will be complied with by a health practitioner at a future date if no agent is designated. To this extent, patient health care decisions expressed in an advance directive are not grounded in contemporaneous informed consent to the same extent as in Ontario.

Alberta's legislation sits somewhere between Ontario's and British Columbia's on a spectrum. For most patients, Alberta legislation prescribes that a personal directive is to be interpreted by the appointed proxy (like Ontario). However, the *Personal Directives Act* also provides that a personal directive will be followed where there is no agent appointed pursuant to that directive (in priority to a default statutory SDM).

From a policy perspective, Alberta legislation removes some of the risks that future care wishes will be applied mechanically and without reference to the patient's present health conditions by health practitioners. However, from a practical perspective this legislation might force patients to make a choice

between giving a proxy directive and an instructional directive. Where a patient has appointed an agent under a personal directive, the directive is to be interpreted by the agent. Where no agent is appointed, the personal directive is acted upon by treating health practitioners.

Where there is no personal directive and no agent appointed, default SDMs are not required to follow applicable prior capable wishes. This is a confusing policy choice: Alberta legislation puts a great deal of emphasis on formalized advance directives, but very little emphasis on informal advance directives. At the same time, Alberta's legislation is both creating the risk that advance directives will be mechanically applied without reference to the patient's present health condition (where an advance directive is in place with no agent), but also creates the risk that applicable patient wishes will not be followed by a default SDM (where no advance directive is in place). In the opinion of the authors, Ontario's legislative model is more flexible, and consistently balances the effect of prior capable wishes (both formal and informal) with informed consent.

D. Nova Scotia

1. Is there a statutory provision setting out the requirement to obtain informed consent?

In Nova Scotia, there is no statute setting out an overarching requirement to obtain informed consent and codifying the matters that must be disclosed to the patient. However, with respect to treatment in a hospital, the *Hospitals Act* provides that "No person admitted to a hospital or a psychiatric facility shall

receive treatment unless he consents to such treatment.”¹⁹⁷ Of course, the common law of informed consent to treatment also continues to apply in Nova Scotia.

2. Is there a statutory mechanism for creating an advance directive?

Similar to the other jurisdictions reviewed, Nova Scotia has formalized advance directive legislation. Nova Scotia’s *Personal Directives Act* enables a person to create instructions or an expression of values, beliefs and wishes about future personal-care decisions to be made on his or her behalf, and to authorize a delegate to make personal-care decisions on his or her behalf.¹⁹⁸ This instruction is called a “personal directive” and must comply with the requirements set out by the statute.¹⁹⁹

Interestingly, Nova Scotia’s *Medical Consent Act* (repealed in 2010) also permitted patients to authorize another person of the age of majority to give consent or directions respecting medical treatment.²⁰⁰ Authorizations made under the *Medical Consent Act* will remain effective, despite the enactment of the *Personal Directives Act*.²⁰¹

3. What is the legal effect of an advance directive?

The *Personal Directives Act* does not contain a provision equating advance directives with informed consent to treatment, or stating that a personal directive has the same effect as a decision made by the patient when capable (as we will see in other jurisdictions). The legal effect of a personal directive is a function of its interpretation by a delegate making decisions on behalf of the

incapable patient, and the circumstances in which a service provider may comply with a directive without receiving substitute consent from a representative of the patient, as set out below.

4. Who interprets and applies the advance directive?

Similar to Alberta, in Nova Scotia a personal directive is interpreted and applied by the appointed delegate, unless the directive does not appoint an agent, or that agent is not available. In those latter circumstances, a personal directive is interpreted by a treating service provider. In making decisions under a personal directive, the delegate must:

- (a) follow any instructions in a personal directive unless
 - (i) there were expressions of a contrary wish made subsequently by the maker who had capacity,
 - (ii) technological changes or medical advances make the instruction inappropriate in a way that is contrary to the intentions of the maker, or
 - (iii) circumstances exist that would have caused the maker to set out different instructions had the circumstances been known based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions;
- (b) in the absence of instructions, act according with what the delegate believes the wishes of the maker would be based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions;
- (c) where the delegate does not know the wishes, values and beliefs of the maker, make the personal-care decision that

the delegate believes would be in the best interests of the maker.²⁰²

In addition to the obligations placed on delegates, the *Personal Directives Act* places obligations on health practitioners. Health practitioners must ask whether a patient has made a personal directive prior to soliciting the decision of a statutory decision-maker and, if a personal directive exists, the health practitioner must request a copy of the directive and include it in the maker's health record.²⁰³ A health practitioner is mandated to follow any instructions by a delegate who is acting in accordance with his or her stipulated duties.²⁰⁴ If no delegate has been authorized, the health practitioner must follow the instructions or expression of the maker's wishes set out in a personal directive.²⁰⁵ Where no delegate nor instructions or expression of wishes are set out in a personal directive, the health practitioner must follow the instruction of a statutory decision-maker.²⁰⁶

Unless a personal directive has been created without appointing a delegate, or the delegate is not available, the delegate will be responsible for interpreting the personal directive. Where there is no delegate, but there is a personal directive, the service provider is tasked with interpreting the advance directive to determine how it will be applied.

5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

Nova Scotia legislation draws a distinction between the effect of a formalized written personal directive, and other informal expressions of wishes,

values and beliefs. As noted above, a service provider may follow instructions contained in a personal directive where there is no delegate.

Other informally expressed wishes are interpreted by the patient's delegate, who must make the decision based on what the proxy believes the wishes of the maker would be, based on what the proxy knows of the values and beliefs of the maker and from any other written or oral instructions. If the delegate does not know of the wishes, value, and beliefs of the maker, he/she is instructed to make the decision that the delegate believes would be in the best interests of the maker.²⁰⁷

To the extent that Nova Scotia allows personal directives to be implemented by service providers, and directs delegates to first apply instructions contained in personal directives, Nova Scotia prioritizes instructions and wishes contained in a personal directive over the informally expressed wishes, values, and beliefs of the patient.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

Where an adult lacks the capacity to make decisions concerning health care, placement in a continuing care home, or home care decisions and has not created a personal directive, a statutory decision-maker is selected from a hierarchy set out in the *Personal Directives Act*.²⁰⁸ A nearest relative may be selected as the statutory decision-maker, provided that relative complies with the other statutory requirements.²⁰⁹ The statutory decision-maker must base his or her decision on what he/she believes the wishes of the adult would be,

considering the known values and beliefs of the adult and any other written or oral instructions.²¹⁰ If the statutory decision-maker is not aware of the wishes, values and beliefs of the adult, he or she must act according to what would be in the best interests of the adult.²¹¹

The Nova Scotia *Hospitals Act* contains a similar hierarchy of SDMs for when a patient is found to be incapable.²¹²

7. How are disputes resolved?

Where there is a dispute relating to substitute decision-making, the *Personal Directives Act* provides that court applications may be brought for, *inter alia*, directions with respect to a personal directive.²¹³

Where the patient is in hospital, the *Hospitals Act* provides for court applications to review decisions made by SDMs to ensure that the SDM has rendered a capable informed consent, and to review a finding of incapacity.²¹⁴ While Nova Scotia created a Review Board pursuant to its *Involuntary Psychiatric Treatment Act*, the jurisdiction of this board has not been expanded to apply to patients generally found incapable of consent or refusing treatment.²¹⁵

8. Summary and Commentary

As in Alberta, health practitioners in Nova Scotia are mandated to follow the instructions set out in the personal directive in certain circumstances, apparently regardless of whether those instructions reflect a decision based on informed consent.

From a policy perspective, Nova Scotia sits somewhere between Ontario and British Columbia: personal directives are acted upon directly by health practitioners but only where no agent is appointed. It is unclear what policy considerations resulted in personal directives being interpreted and acted upon by health practitioners, but only where no agent is appointed. It is possible that this model resulted from practical considerations around health care decision-making (for example, it being more efficient to implement a personal directive through a health practitioner rather than requiring health practitioners to locate a default SDM to interpret the directive).

Nova Scotia also has the same divergent effects for formal and informal future care wishes as Alberta: informal wishes are only “considered” by default SDMs and need not necessarily be followed where applicable. It is similarly unclear what factors Nova Scotia was attempting to balance in arriving at this legislative model. It is possible that this model was the result of some scepticism around the usefulness of informally expressed wishes.

In the opinion of the authors, Nova Scotia’s legislative model could benefit from a consistent approach to future care wishes that would apply across all SDMs, as is the case in Ontario.

E. Saskatchewan

1. Is there a statutory provision setting out the requirement to obtain informed consent?

Saskatchewan has not codified the requirement to obtain informed consent or the matters that must be discussed with the patient or SDM. The

common law of informed consent, set out above, continues to apply in Saskatchewan.

2. Is there a statutory mechanism for creating an advance directive?

Like the other provinces reviewed, Saskatchewan has passed specialized advance directive legislation in the form of the *Health Care Directives and Substitute Health Care Decision Makers Act*. This *Act* permits any person to create a written “directive” regarding future health care decisions and/or that appoints a proxy decision-maker.²¹⁶

3. What is the legal effect of an advance directive?

If a directive contains a direction for a health care decision concerning treatment for a clearly anticipated, specific circumstance, the directive is recognized as having the same effect as a decision made by a person who has the capacity to make the health-care decision.²¹⁷ If the directive does not clearly anticipate and provide instruction for a specific circumstance, the directive is used for the purposes of guidance as to the maker’s wishes.²¹⁸

4. Who interprets and applies the advance directive?

It is the duty of an appointed proxy to make health care decisions in accordance with wishes expressed by the person prior to becoming incapable.²¹⁹ If unaware of the person’s wishes, a proxy may act in accordance to what he or she believes to be in the best interest of the person.²²⁰ As such, where a proxy is

consulted, the statute envisages that an advance directive is interpreted and applied by that proxy.

It is unclear how the statutory provision stating that an advance directive has the same effect as a decision made by a person who has the capacity to make the health care decision will effect who interprets the applicability of an advance directive.²²¹ This language could be interpreted to mean that an advance directive is equivalent to consent to treatment, and therefore that the advance directive can be acted upon directly by a treating health practitioner. This interpretation is supported by the fact that “health-care decision” is defined in the legislation as: “a consent, refusal of consent or withdrawal of consent to treatment.”²²² However, this language could also mean that the applicability of an advance directive is interpreted by the designated proxy, and that any applicable directive binds the proxy.

A related point is that Saskatchewan’s legislation is unclear on whether a health practitioner can take direction from an uninformed “health-care decision.” For example, imagine a patient made a valid directive accepting a particular treatment without any knowledge of the risks and benefits of that treatment. If that patient subsequently became incapable and a physician proposed that particular treatment, would the physician be required to obtain informed consent or could he/she just rely on the directive and provide the treatment? At common law, the physician is still required to obtain informed consent. However, the legislation defines a health care decision as a “consent”. While this issue is open

to debate, it would seem that Saskatchewan legislation permits uninformed advance directives to be given effect.

5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

The *Health Care Directives and Substitute Health Care Decision Makers Act* draws a distinction between health care decisions contained in a formal directive and other wishes, values and beliefs of the patient. The *Act* provides that a health care decision in a directive that “clearly anticipates and gives directions relating to treatment for the specific circumstances that exist” has the same effect as a capable decision of the patient.²²³ While proxies have an obligation to comply with other informally expressed wishes, these wishes are not themselves equated with a capable decision of the patient.²²⁴ To this extent, the *Act* prioritizes health care decisions set out in an advance directive over informally expressed wishes, values and beliefs of the patient.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

When an individual lacks the capacity to give or refuse consent to health care and has not created an applicable personal directive, a “nearest relative” may be selected to make a substitute health care decision provided that no proxy or personal guardian has been appointed or the appointed proxy/person guardian is unavailable, unwilling or incapable of making the decision.²²⁵ The nearest relative is an individual who is available, willing and capable of making health care decisions and is selected from a hierarchy.²²⁶ A nearest relative must act according to the wishes expressed by the person prior to becoming incapable or,

if unaware of the person's wishes, according to what would be in the best interests of the person.²²⁷

If there is no nearest relative, or a nearest relative is not found through reasonable attempts by a treatment provider, treatment may be provided without consent to the extent that is reasonably necessary and in the best interests of the person if the treatment provider believes that the treatment is necessary and another treatment provider agrees in writing.²²⁸

7. How are disputes resolved?

The *Health Care Directives and Substitute Health Care Decision Makers Act* provides that any interested person may apply to Court for a remedy if they believe a proxy or SDM is not acting in good faith or in accordance with the *Act*.

On such an application, the Court may:

- (a) suspend or terminate the appointment of the proxy or the authority of the nearest relative and rescind any health care decision made by the proxy or nearest relative;
- (b) in the case of a proxy, substitute the court's health care decision for any health care decision made by the proxy, except where the directive appoints at least one other proxy who is willing, available and capable to make a health care decision; and
- (c) in the case of a nearest relative, appoint another person from the list set out in subsection 15(1) to make a health care decision.²²⁹

8. Summary and Commentary

A health directive is equivalent to a decision of the patient. However, it is unclear if this decision can be acted upon directly by a health practitioner or must go through the appointed proxy. The language of the *Act* strongly suggests that

such decisions are given effect directly by a health practitioner, but this appears to be an issue that is open for debate. On a related issue, the common law in Saskatchewan continues to require informed consent before a physicians can provide treatment, and it is unclear whether this legislation was meant to abrogate from that requirement where a patient has issued an uninformed directive.

If a health directive does not apply to the circumstances, it is interpreted by the proxy as part of determining the patient's best interest. Where a patient is incapable, does not have a health directive, and does not have a nearest relative, a health practitioner may provide treatment without consent provided another health practitioner agrees.

Like British Columbia, Saskatchewan has conceptually prioritized patient autonomy to direct future treatment over the patient's right to give or refuse informed consent to treatment. However, in the authors' opinion, patient autonomy is not truly furthered by permitting patients to be bound by uninformed wishes about future care.

While it seems that Saskatchewan has made a policy decision to allow health practitioners to give effect to health directives, the legislation does not say so clearly. As such, it is difficult to speculate about exactly what policy factors Saskatchewan was balancing when drafting its legislation. As noted above with regard to British Columbia, allowing patients to pre-consent or refuse treatments is a rule that is easy to follow for health practitioners. This rule also likely saves

time and effort that would otherwise be spent by health practitioners locating and informing SDMs of the patient's present condition and his/her wishes. Arguably, this is also more in keeping with patient autonomy because patients are able to directly decide the care they will be provided in the future. However, it may have the practical effect of restricting patient autonomy by binding patients to wishes made without the benefit of critical health information.

The potential downside of Saskatchewan's legislative model is that patients may be trapped by uninformed and inapplicable wishes. Health practitioners will likely have only passing contact with a patient, and not know the patient's actual understanding of the treatments pre-selected or refused or the assumptions that underlay the advance directive.

F. England

1. Is there a statutory provision setting out the requirement to obtain informed consent?

In England, the requirement for health practitioners to obtain informed consent before administering treatment has not been set out in statute and is governed by the common law.

2. Is there a statutory mechanism for creating an advance directive?

The English *Mental Capacity Act 2005*²³⁰ outlines several different advance care planning methods: including 'advance decisions', other informal expressions of wishes and feelings, and lasting powers of attorney appointing a "donee".

An advance decision refers to a decision that was made by a person 18 years of age or older (with the requisite capacity) to refuse (but not consent to) a specified treatment that may be proposed at a time when he/she no longer has capacity.²³¹

The *Mental Capacity Act 2005* also allows a person to create a lasting power of attorney, granting authority to another person (a 'donee') to make decisions concerning specified matters of personal welfare and/or property and affairs on behalf of the maker when he or she no longer has capacity.²³²

In the alternative to selecting a donee under a power of attorney, a deputy may be appointed by the court to act as the person's agent with respect to anything done or decided by him or her within the scope of the designated appointment.²³³ A deputy must be 18 years of age or older or, with respect to powers of property and affairs, a trust corporation.²³⁴ Deputies and donees are subject a number of restrictions laid out in the *Act*.²³⁵

The *Mental Capacity Act 2005* also contemplates that patients will express informal wishes, values, and beliefs about health care, and that those statements will be considered by individuals making decisions on the patient's behalf, as set out below.²³⁶

3. *What is the legal effect of an advance directive?*

When an advance directive (called an 'advance decision') is valid and applicable to a particular circumstance, it has the same effect as if the decision was made with capacity at the time the question for treatment was posed.²³⁷

However, an advance decision can only refuse, and not consent to, treatment (e.g. the advance decision can only state that the patient does not want a particular treatment). Notably:

- An advance decision will prevail over a lasting power of attorney, unless the person has provided authority to give and refuse consent with respect to the specific treatment of which the advance decision refers to in the lasting power of attorney.²³⁸
- The *Act* does not specify a need for the advance decision to be made in writing, unless it is a decision to refuse life-sustaining treatment.
- An advance decision refusing life-sustaining treatment must be verified by a statement of confirmation by the individual that the decision shall apply even if life is at risk. The statement must be in writing, signed by the individual (or another in the presence of the individual at the individual's direction), the signature is made in the presence of a witness, and the witness signs it in the presence of the individual.²³⁹

Unlike an “advance decision”, other expressions of wishes and feelings are not legally binding. Such expressed wishes and feelings must be considered when determining the best interest of an individual when he or she is incapable of providing or refusing consent. However, there is no strict legal duty to comply with these wishes and feelings.²⁴⁰

Power granted by a lasting power of attorney is subject to the conditions set out in the lasting power of attorney.²⁴¹ There are some restrictions to the power that may be granted to an attorney. One such restriction is the authority to restrain the donor, unless the circumstances meet prescribed conditions.²⁴² Similarly, the authority granted in a lasting power of attorney for personal welfare does not extend to making decisions in circumstances other than when the donor lacks capacity or the donee reasonably believes the donor to lack capacity.²⁴³

The authority granted also does not authorise the giving or refusing of consent to life-sustaining treatment, unless specifically provided for in the document.²⁴⁴

4. *Who interprets and applies the advance directive?*

The legally binding *Code of Practice* prepared pursuant to the *Mental Capacity Act* provides that the applicability of an advance decision to refuse treatment will be considered by a treating “healthcare professional,” and not by a representative of the patient. As an example, the *Code of Practice* provides that:

So when deciding whether an advance decision applies to the proposed treatment, healthcare professionals must consider:

- how long ago the advance decision was made, and
- whether there have been changes in the patient’s personal life (for example, the person is pregnant, and this was not anticipated when they made the advance decision) that might affect the validity of the advance decision, and
- whether there have been developments in medical treatment that the person did not foresee (for example, new medications, treatment or therapies).²⁴⁵

In providing guidance for when there is a disagreement about the effect of an advance decision, the *Code of Practice* expressly provides that the healthcare professional is responsible for interpreting the advance decision:

9.64 It is ultimately the responsibility of the healthcare professional who is in charge of the person’s care when the treatment is required to decide whether there is an advance decision which is valid and applicable in the circumstances. In the event of disagreement about an advance decision between healthcare professionals, or between healthcare professionals and family members or others close to the person, the senior clinician must consider all the available evidence. This is likely to be a hospital consultant or the GP where the person is being treated in the community.

9.65 The senior clinician may need to consult with relevant colleagues and others who are close to or familiar with the patient. All staff involved in the person’s care should be given the opportunity to express their

views. If the person is in hospital, their GP may also have relevant information.

9.66 The point of such discussions should not be to try to overrule the person's advance decision but rather to seek evidence concerning its validity and to confirm its scope and its applicability to the current circumstances. Details of these discussions should be recorded in the person's healthcare records. Where the senior clinician has a reasonable belief that an advance decision to refuse medical treatment is both valid and applicable, the person's advance decision should be complied with.²⁴⁶

It would appear that, in England, advance decisions are followed directly by health practitioners.

Where a patient has appointed a donee under a lasting power of attorney, the donee is responsible for interpreting and applying the patient's prior capable wishes as part of the best interest analysis – unless that patient has created a binding advance decision and the lasting power of attorney does not specifically grant authority over this particular treatment to the donee.²⁴⁷ Similarly, a court appointed deputy is required to act in accordance with patient's best interests.²⁴⁸

As set out below, where there is no donee or court appointed deputy, a healthcare provider will act as decision-maker for the incapable patient applying the best-interests test and considering the patient's past and present wishes.

In accordance with the *Mental Capacity Act 2005*, 'best interests' means considering all the relevant circumstances and taking the following steps:

(2)The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

(3)He must consider—

- (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
- (b) if it appears likely that he will, when that is likely to be.

(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

(6) He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

(7) He must take into account, if it is practicable and appropriate to consult them, the views of—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b) anyone engaged in caring for the person or interested in his welfare,

(c) any donee of a lasting power of attorney granted by the person, and

(d) any deputy appointed for the person by the court,

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).²⁴⁹

In England, advance decisions are interpreted by healthcare professionals. If there is no advance decision, the patient's wishes are considered as part of the best-interests test, which may be applied by either a donee, court appointed deputy, or a healthcare professional.

5. Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

The *Mental Capacity Act 2005* distinguishes between the effect of advance directives and other informally expressed wishes, values, and beliefs. An advance directive has the same effect as a decision of the patient made with capacity. More informal expressions of wishes, values, and beliefs are only considered by the incapable patient's decision-maker as part of the best interests analysis. There is no statutory requirement for these informally expressed wishes to be complied with where they are applicable (as is also the law in Ontario). The *Mental Capacity Act 2005* provides that a decision-maker must consider:

- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.²⁵⁰

Interestingly, as set out in the above quote, the *Act* also seems to prioritize (or at least emphasize) written capable wishes and feelings over other orally expressed wishes and feelings.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

The *Code of Practice* explains that, in general, the incapable patient's decision-maker will be the health practitioner, unless a donee or deputy has been appointed:

5.8 Under the Act, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to throughout this chapter, and in other parts of the Code, as the ‘decision-maker’, and it is the decision-maker’s responsibility to work out what would be in the best interests of the person who lacks capacity.

- For most day-to-day actions or decisions, the decision-maker will be the carer most directly involved with the person at the time.
- Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.
- Where nursing or paid care is provided, the nurse or paid carer will be the decision-maker.
- If a Lasting Power of Attorney (or Enduring Power of Attorney) has been made and registered, or a deputy has been appointed under a court order, the attorney or deputy will be the decision-maker, for decisions within the scope of their authority.²⁵¹

Interestingly, the English legislation provides that an independent mental capacity advocate will be appointed to advocate for the incapable patient (unless there is insufficient time). The submissions of this advocate must be considered by the healthcare professional.²⁵²

7. How are disputes resolved?

The *Mental Capacity Act 2005* creates a superior court of record called the Court of Protection.²⁵³ This Court has the authority on an application to, *inter alia*:

- decide whether a person has capacity to make a particular decision for themselves
- make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make such decisions
- appoint deputies to make decisions for people lacking capacity to make those decisions
- ...
- remove deputies or attorneys who fail to carry out their duties.²⁵⁴

Specifically, the Court of Protection may interpret an advance decision, and has urgent procedures that operate 24 hours a day in case of emergency.²⁵⁵

8. Summary and Commentary

England provides an interesting example of a model for health care consent and substitute decision-making that is very different from Ontario. For incapable patients, English law gives a great deal of authority to health practitioners to decide what is in the patient's best interest, rather than an obligation to obtain informed consent from a default SDM. As the British Medical Association explains in its "Consent Tool Kit":

In England and Wales, the Mental Capacity Act allows people over 18 years of age, who have capacity, to make a Lasting Power of Attorney appointing a welfare attorney to make health and personal welfare decisions on their behalf once capacity is lost. The Court of Protection may also appoint a deputy to make these decisions. Neither welfare attorneys or deputies can demand treatment which is clinically inappropriate. Where there is no welfare attorney or deputy the doctor may treat a patient who lacks capacity, without consent, providing the treatment is necessary and in the patient's best interests. The Act also requires doctors to take into account, so far as is reasonable and practicable, the views of the patient's primary carer...[Emphasis added]²⁵⁶

In England, health practitioners are required to consult far and wide but, absent an attorney or deputy, are the patient's decision-maker and consent is not required.

In the very recent case of *Aintree University Hospitals NHS Foundation Trust v. James*, the UK Supreme Court summarized the basic law of consent to treatment, substitute decision-making, and the operation of the *Mental Capacity Act, 2005*:

...Generally it is the patient's consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment. Nor is it lawful to treat a patient who lacks capacity if he has made a valid and applicable advance decision to refuse it: see 2005 Act, sections 24 to 26. Nor is it lawful to treat such a patient if he has granted a lasting power of attorney (under section 10) or the court has appointed a deputy (under section 16) with the power to give or withhold consent to that treatment and that consent is withheld; but an attorney only has power to give or withhold consent to the carrying out or continuation of life-sustaining treatment if the instrument expressly so provides (section 11(8)) and a deputy cannot refuse consent to such treatment (section 20(5)).

...

A person who has the capacity to decide for himself can of course make decisions which are not in his own best interests and no doubt frequently does so. Indeed, the Act provides that a person is not to be treated as unable to make a decision simply because he makes an unwise one: section 1(4). But both at common law and under the Act, those who act or make decisions on behalf of a person who lacks capacity must do so in his best interests...²⁵⁷

From a policy perspective, England has apparently reached very different conclusions than Ontario. While Ontario stresses authenticity of substitute decision-making by a default hierarchy of close family members, England did not create such a hierarchy. Instead, unless a formalized proxy decision-maker has been appointed, the health practitioner acts as decision-maker.

Whereas the Fram Report concluded that, for Ontario, health practitioners should not be asked to decide the value of their services to the patient, England seems quite comfortable with leaving these decisions with health practitioners. One potential benefit of England's model is that it relieves lay decision-makers not appointed by the patient of the need to know their legal role and how they are to consider the patient's prior capable wishes. Instead, the patient's family and friends become points of reference for the health practitioner in consulting and understanding the patient's best interest. However, it seems that the health

practitioner is not required to obtain informed consent from anyone where the health practitioner is the decision-maker.

Another interesting side to England's legislative model is that health practitioners are tasked with interpreting advance decisions. The primary benefit of this model appears to be that it is simple and efficient. A health practitioner considering whether to administer treatment can review an advance decision, and determine whether it is applicable. There is no need to speak to an SDM to explain the content of the advance decision and the SDM's obligations. However, the effect of this policy decision is somewhat lessened by the fact that advance decisions only apply to refusals, and cannot be used to consent to treatment. To this extent, the applicability of advance decisions in England cannot override informed consent to treatment and, from a practical perspective, are likely most utilized in emergencies where life-sustaining treatment is being withheld.

Ontario's model, on the other hand, provides an express carve-out for emergencies, in which health practitioners may interpret prior capable wishes. Where there is no emergency, Ontario law streams all prior capable wishes through the default SDM in giving informed consent to treatment. This model is more contextual and, in the conclusion of the Fram Report, is less intrusive than and disruptive than some of the alternatives considered.

G. Queensland, Australia

1. *Is there a statutory provision setting out the requirement to obtain informed consent?*

In Queensland, the *Civil Liability Act* sets out the requirement to obtain informed consent, which if not met will result in liability for the treating physician:

21 Proactive and reactive duty of doctor to warn of risk

(1) A doctor does not breach a duty owed to a patient to warn of risk, before the patient undergoes any medical treatment (or at the time of being given medical advice) that will involve a risk of personal injury to the patient, unless the doctor at that time fails to give or arrange to be given to the patient the following information about the risk—

(a) information that a reasonable person in the patient's position would, in the circumstances, require to enable the person to make a reasonably informed decision about whether to undergo the treatment or follow the advice;

(b) information that the doctor knows or ought reasonably to know the patient wants to be given before making the decision about whether to undergo the treatment or follow the advice.

(2) In this section—

patient, when used in a context of giving or being given information, includes a person who has the responsibility for making a decision about the medical treatment to be undergone by a patient if the patient is under a legal disability.

While Queensland has numerous statutes that address health care decision-making for individuals who lack capacity, these statutes do not otherwise codify the requirement to obtain informed consent and the matters that must be discussed with patients.

Interestingly, Queensland legislation provides that consent is not necessarily required on behalf of incapable patients for “minor and uncontroversial” treatments, in some circumstances.²⁵⁸

2. Is there a statutory mechanism for creating an advance directive?

In Queensland, the *Powers of Attorney Act 1998* allows adults to create “advance health directives”. An advance health directive is defined as a document containing directions for a principal’s health care.²⁵⁹ The *Act* prevents an individual from making a directive to withhold or withdraw life-sustaining measures, unless he or she falls within a number of prescribed circumstances – such as a patient suffering from a terminal illness.²⁶⁰ Under the *Powers of Attorney Act 1998*, an individual may also designate an attorney to make decisions for them in the event he/she becomes incapable.²⁶¹

Beyond the formalized “advance directive” document, the Queensland *Powers of Attorney Act 1998* also envisages that patients will informally express wishes with respect to health care in any form, including orally, that will be considered by SDMs.²⁶²

3. What is the legal effect of an advance directive?

In Queensland, decisions made in an advance health directive will “act as their SDM at a time when they no longer have capacity.”²⁶³ The *Act* provides that an advance health directive is as effective as if:

- (i) the principal gave the direction when decisions about the matter needed to be made; and

(ii) the principal then had capacity for the matter.²⁶⁴

This language would appear to suggest that an advance health directive in Queensland will be equivalent to informed consent, and may be acted upon directly by health practitioners.

The Queensland *Guardianship and Administration Act 2000* works in conjunction with the *Power of Attorney Act 1998* in governing decision-making for incapable adults. The *Guardianship and Administration Act 2000* provides the following hierarchy for determining health matters for incapable adults:

66 Adult with impaired capacity—order of priority in dealing with health matter

(1) If an adult has impaired capacity for a health matter, the matter may only be dealt with under the first of the following subsections to apply.

(2) If the adult has made an advance health directive giving a direction about the matter, the matter may only be dealt with under the direction.

(3) If subsection (2) does not apply and the tribunal has appointed 1 or more guardians for the matter or made an order about the matter, the matter may only be dealt with by the guardian or guardians or under the order.

(4) If subsections (2) and (3) do not apply and the adult has made 1 or more enduring documents appointing 1 or more attorneys for the matter, the matter may only be dealt with by the attorney or attorneys for the matter appointed by the most recent enduring document.

(5) If subsections (2) to (4) do not apply, the matter may only be dealt with by the statutory health attorney.

(6) This section does not apply to a health matter relating to health care that may be carried out without consent under division 1.²⁶⁵

According to the above hierarchy, the effect of a valid advance health directive in Queensland appears to be to remove the requirement to obtain consent from an SDM, as the health matter may only be dealt with under the direction. As such, it would appear that an advance directive may be acted upon directly by a patient's health care team, without the need for an intermediary.²⁶⁶

4. Who interprets and applies the advance directive?

The statutory provisions stating that a direction in an advance health directive is as effective as a capable decision made by the principal (quoted above) suggests that a directive may be interpreted and implemented directly by a health practitioner in Queensland. Moreover, the legislation plainly contemplates that a person, other than an attorney appointed under an advance health directive, will be interpreting a relying upon a directive -- as it protects such a person from liability to the same extent as if consent was obtained:

A person, other than an attorney, acting in accordance with a direction in an advance health directive, or a decision of an attorney for a health matter, is not liable for an act or omission to any greater extent than if the act or omission happened with the principal's consent and the principal had capacity to consent.²⁶⁷

Similarly, the statutory guidance published by the Queensland state government provides that an advance directive is to be “respected and followed and takes precedence over healthcare requests made by family members or substitute decision-makers” [emphasis added].²⁶⁸ As noted above, an advance directive also occupies the highest rung in the hierarchy for determining how health

matters will be decided. These provisions strongly suggest that an advance directive will be interpreted and implemented directly by health practitioners.

However, the legislation also expressly contemplates that an attorney will interpret and apply statements in an advance health directive in certain circumstances. The *Powers of Attorney Act 1998* provides that attorneys appointed pursuant to a health direction must comply with certain principles in making decisions for incapable patients, including the “health care principle”.²⁶⁹

Health care principle

(1) The **health care principle** means that power for a health matter for an adult should be exercised by an attorney—

(a) in the way least restrictive of the adult’s rights; and

(b) only if the exercise of power—

(i) is necessary and appropriate to maintain or promote the adult’s health or wellbeing; or

(ii) is, in all the circumstances, in the adult’s best interests.

(2) In deciding whether the exercise of a power is appropriate, the attorney must, to the greatest extent practicable—

(a) seek the adult’s views and wishes and take them into account; and

(b) take the information given by the adult’s health provider into account.

(3) The adult’s views and wishes may be expressed orally, in writing (for example, in an advance health directive) or in another way, including, for example, by conduct.

(4) The health care principle does not affect any right an adult has to refuse health care.²⁷⁰ [Emphasis added]

This language suggests that there are circumstances in which an SDM will interpret views and wishes in an advance directive in giving or refusing consent

to treatment. It would appear that the Queensland legislation draws a distinction between “views and wishes” expressed in an advance directive and a “direction” given in an advance direction: the latter can be followed by a health practitioner as determinative of a health matter while the former is to be interpreted by an SDM in complying with the health care principle.

5. Is there a legal distinction between an ‘advance directive’ and other informal expressions of wishes, values and beliefs?

Queensland legislation draws a distinction between a formalized advance health directive and other expressions of wishes, values, and beliefs. As noted above, under the *Guardianship and Administration Act 2000*, formalized advance health directives are determinative of decisions about health matters. Informal expressions of “views and wishes” are to be considered by an attorney in making decisions in accordance with the “health care principle,” discussed above. It would appear that the Queensland legislation draws a distinction between “views and wishes” expressed in an advance directive and a “direction” given in an advance direction: the latter is binding while the former is not.

In Queensland, directions in an advance health directive appear to be prioritized over other informally expressed wishes, values, and beliefs, and also prioritized over “views and wishes” expressed in an advance directive.

6. Who makes decisions for an incapable patient who has not appointed a proxy?

Like the law in Ontario, the *Powers of Attorney Act 1998* creates a statutory hierarchy of default decision-makers referred to as a “Statutory Health

Attorney” for when a patient lacks capacity (and does not have an advance health directive).²⁷¹ These statutory health attorneys are required to make decisions in accordance with the health care principle, set out above.

7. How are disputes resolved?

Similar to the CCB in Ontario, Queensland has created a specialized tribunal with authority to resolve a variety of disputes regarding the administration of health care to incapable persons, the withdrawal of life-sustaining treatments, and the appointment of “guardians” to make health care decisions for incapable persons. From the authors’ review of the legislation, it would appear that this tribunal, called the Queensland Civil and Administrative Tribunal, offers a relatively quick and streamlined application process.²⁷²

8. Summary and Commentary

In Queensland, patients are able to express written directives that are interpreted and applied directly by health practitioners in non-emergencies. As will become a recurring theme in this report, the absence of an express statutory mechanism for creating and implementing advance directives, and the role of the SDM as the near exclusive interpreter of a patient’s prior capable wishes, appear to be defining and unique features of Ontario’s legal regime.

As have British Columbia and Saskatchewan, Queensland has prioritized patient autonomy to direct future treatment over the patient’s right to give or refuse informed consent to treatment. Interestingly, Queensland has gone so far as to make an advance health directive its own rung on the hierarchy for dealing

with a health care matter – the health practitioner need not turn to an SDM if an advance health directive is in place. This rule is easy to follow for health practitioners and also likely saves time and effort that would otherwise be spent by health practitioners locating and informing SDMs. The other primary benefit of this legislative model is that it respects patient autonomy, by permitted patients when capable to guide their future care with binding effect.

As noted above, the drawback to Queensland’s legislative model is that patients may be trapped by uninformed and inapplicable wishes. Health practitioners will likely have only passing contact with a patient, and are for that reason are unlikely to know the patient’s actual understanding of the treatments pre-selected or refused or the assumptions that underlie the advance health directive.

H. United States

1. Introduction

In the United States, advance directives are recognized at the federal level and by all 50 states and the District of Columbia.²⁷³ The content of an individual’s rights under an advance directive, together with the attendant processes and procedures, are regulated by state law.²⁷⁴ Most states today recognize both instruction directives and proxy directives.²⁷⁵ In preparing this Paper, we examined the laws of the states of Hawaii, Oregon, and Texas.

2. Physician Orders for Life Sustaining Treatment (POLST)

Responding to concerns regarding how to implement advance directives in unexpected or emergency situations, many states have implemented the Physician Order for Life-Sustaining Treatment statutory scheme.

The POLST (and its variations) is meant to work in tandem with an advance directive, by providing physician-signed instructions and orders regarding the patient's current, short-term health preferences, under a narrow set of circumstances. It is designed to provide a legally binding document, which health practitioners, including emergency medical staff, are authorized to follow even outside hospital settings. It is not meant to take the place of the advance directive.²⁷⁶

Each state determines its own requirements and provisions regarding advance directives. While some common templates are available, it is up to each state to determine whether and to what degree to implement them.

3. The Conscience Objection

All three states reviewed allow health practitioners to refuse to comply with advance directives involving the withdrawal and withholding of life sustaining treatments. These are commonly referred to as "conscience objection" provisions. For example, Oregon legislation provides:

(1) No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the withdrawal or withholding of life-sustaining procedures or of artificially administered nutrition or hydration.

(2) If a health care provider is unable or unwilling to carry out a health care instruction or the decisions of the health care representative, the following provisions apply:

(a) The health care provider shall promptly notify the health care representative, if there is a health care representative;

(b) If the authority or decision of the health care representative is in dispute, the health care representative or provider may seek the guidance of the court in the manner provided in ORS 127.550 (Petition for judicial review of advance directives);

(c) If the representative's authority or decision is not in dispute, the representative shall make a reasonable effort to transfer the principal to the care of another physician or health care provider; and

(d) If there is no health care representative for an incapable patient, and the health care decisions are not in dispute, the health care provider shall, without abandoning the patient, either discharge the patient or make a reasonable effort to locate a different health care provider and authorize the transfer of the patient to that provider.²⁷⁷

As could be expected, we understand that these provisions place a great deal of discretion in the hands of health practitioners in practice to refuse to comply with advance directives. These provisions are apparently meant to address moral and religious objections to participation in the withdrawal of life-sustaining treatments.

4. Hawaii

(a) Is there a statutory provision setting out the requirement to obtain informed consent?

In 1993, the National Conference of Commissioners on Uniform State Law drafted *the* Uniform Health Care Decisions Act, which has since been adopted by a number of states including by Hawaii.²⁷⁸

Like all American states, in Hawaii capable adults generally have the right to make their own medical decisions.²⁷⁹ Hawaii has specified the information that must be provided to patients in order for informed consent to be given:

§16-85-25 General standards for categories of information. (a) Except as provided in subsection (b), where standards of medical practice indicate that a health care provider should provide the patient, or the patient's guardian, with information prior to obtaining consent for proposed medical or surgical treatment, or for a diagnostic procedure, information satisfying the following categories shall be supplied to the patient or the patient's guardian:

- (1) The condition to be treated or the suspected existence of which is the indication for a diagnostic procedure;
- (2) A description of the proposed medical or surgical treatment or diagnostic procedure;
- (3) The intended and anticipated result;
- (4) The recognized alternative treatments or diagnostic procedures, including the option of not providing treatment or performing the diagnostic procedure;
- (5) The recognized substantial risks of serious complication or mortality associated with the proposed treatment or diagnostic procedure, with the recognized alternative treatments or diagnostic procedures, and with not undertaking treatment or diagnosis; and
- (6) The recognized benefits of the proposed treatment or diagnostic procedure, of recognized alternative treatments or diagnostic procedures, and of not undertaking treatment or diagnosis.

(b) The disclosure of information required by subsection (a) may be withheld if in the judgment of the health care provider the information would be detrimental to the patient's mental or physical health, or not in the best interest of the patient, provided that such action is consistent with general standards of medical and surgical practice.²⁸⁰

Where a patient lacks capacity, Hawaii's *Uniform Health Care Decisions Act (Modified) (1999)* specifies how decisions are to be made for that

individual.²⁸¹ Hawaii has also implemented the POLST system for converting a patient's wishes into portable medical orders that address critical care decisions most relevant to the patient's current advanced condition, through its *Physician Orders for Life Sustaining Treatment Act*.²⁸²

(b) What is the statutory mechanism for creating an advance directive?

Under the *Uniform Health Care Decisions Act*, both adults and emancipated minors can create advance directives.²⁸³ The advance directive allows a person to both create individual instructions and to designate a guardian or agent to make decisions on their behalf under an enduring power of attorney for health care.²⁸⁴ As set out below, Hawaii legislation also envisages that patients will informally express wishes about future care.

(c) What is the legal effect of an advance directive?

Hawaii legislation does not prescribe an overarching effect for advance directives: such as that an advance directive will have the same effect as the consent of a capable patient, or that instructions contained in an advance directive will rank on the hierarchy of SDMs. Instead, the legal effect of advance directives in Hawaii is a function of several different provisions regarding when an advance directive will be given effect, and by whom. These provisions are set out below in our discussion of the interpretation and application of advance directives.

(d) Who interprets and applies the advance directive?

Hawaii's legislation prescribes obligations of both agents appointed under advance directives and health-care providers, with respect to giving effect to instructions in advance directives.

In setting guidelines for decision-making by agents, the statute provides that:

an agent shall make a health care decision in accordance with the principal's individual instructions, if any, and any other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent's determination of the principal's best interest.²⁸⁵

The Hawaii statute defines the term "best interest" as follows:

"Best interest" means that the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from that treatment and shall include:

- (1) The effect of the treatment on the physical, emotional, and cognitive functions of the patient;
- (2) The degree of physical pain or discomfort caused to the individual by the treatment or the withholding or withdrawal of the treatment;
- (3) The degree to which the individual's medical condition, the treatment, or the withholding or withdrawal of treatment, results in a severe and continuing impairment;
- (4) The effect of the treatment on the life expectancy of the patient;
- (5) The prognosis of the patient for recovery, with and without the treatment;
- (6) The risks, side effects, and benefits of the treatment or the withholding of treatment; and
- (7) The religious beliefs and basic values of the individual receiving treatment, to the extent that these may assist the

surrogate decision-maker in determining benefits and burdens.”²⁸⁶

The agent is directed to consider the principal’s personal values, to the extent known to the agent, in determining the patient’s best interests.²⁸⁷ As such, Hawaii legislation plainly contemplates that instructions in advance directives are to be interpreted and applied by SDMs.

However, Hawaii legislation also provides that health-care providers are to:

comply with an individual instruction of the patient, and with a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient.²⁸⁸

The first clause of the above quote requires health-care providers to comply with a patient’s “individual instructions” as distinct from “a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient.” This suggests that there are circumstances in which a health-care provider will be directly interpreting an implementing an individual instruction in an advance directive.

In Hawaii, it would appear that both an agent appointed pursuant to a power of attorney for health care and a health-care provider will, in certain circumstances, be responsible for interpreting and applying an “instruction.” Furthermore, the implementation of an instruction in an advance directive will be subject to the health-care provider’s determination of whether the agent’s interpretation of the instruction is reasonable.

(e) Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

Hawaii law draws a distinction between the effect of instructions contained in an advance directive, and other informal expressions of wishes, values and beliefs. As noted above, where a patient is incapable and has created an advance directive containing individual instructions, both the agent and the health-care provider are obliged to comply with those instructions. However, where the patient has appointed an agent pursuant to an advance directive but has not given individual instructions in that advance directive, or the patient has not created a valid advance directive at all, the health-care provider is not obliged to comply with informally expressed wishes by the patient (but these instructions must still be considered as part of health-care providers' professional ethics). An agent appointed under an advance directive, or the patient's surrogate, are still required to make decisions based on the instructions of the patient.

In this way, Hawaii legislation prioritizes formalized instructions given in an advance directive by specifying that health practitioners are required to comply with such instructions, but not requiring them to comply with informally expressed wishes.

(f) Who makes decisions for an incapable patient who has not appointed a proxy?

In the event that the patient does not have an advance directive appointing a proxy decision-maker, a capable patient may designate an individual to act as surrogate by personally informing the health-care provider.²⁸⁹

The surrogate has authority to make health-care decisions for the patient that the patient could have made on their own behalf.²⁹⁰ This appears to be a very informal statutory mechanism for giving a proxy directive.

If the patient does not have the capacity to designate a surrogate, or the designee is not reasonably available, the patient's 'interested persons'²⁹¹ are tasked with choosing a surrogate by consensus. "Interested persons" is defined as:

the patient's spouse, unless legally separated or estranged, a reciprocal beneficiary, any adult child, either parent of the patient, an adult sibling or adult grandchild of the patient, or any adult who has exhibited special care and concern for the patient and who is familiar with the patient's personal values.²⁹²

It is the physician's responsibility to make reasonable efforts to locate as many interested persons as practicable, but can then leave it up to family members to contact additional persons.²⁹³ Where a surrogate is acting but has not been appointed by a capable patient, the surrogate shall make health care decisions based on the wishes of the patient, or, if the wishes of the patient are unknown or unclear, on the patient's best interest.²⁹⁴ A surrogate who was not designated by the patient, but was chosen by the interested persons, may consent to withdraw or withhold artificial nutrition and hydration only when the primary physician and a second independent physician certify that the act is merely prolonging the act of dying, and that the patient is highly unlikely to have any neurological response in the future.²⁹⁵

(g) How are disputes resolved?

Where this is a dispute around an advance directive, Hawaii legislation allows the patient, the patient's agent, guardian, or surrogate, or a health care provider or institution involved with the patient's care to petition a court of competent jurisdiction, and that court may enjoin or direct a health care decision or order other equitable relief.²⁹⁶

(h) Physician Orders for Life Sustaining Treatment (POLST) Act

Hawaii passed its POLST Act in 2009. As detailed above, the POLST is not intended to replace the advance directive, but rather to provide portable medical orders consistent with the patient's goals and wishes in the short term, under specific circumstances.²⁹⁷ The Act states that the POLST form must be signed by both the patient and physician, or surrogate and physician, and can be executed either by the patient or jointly by the physician and surrogate.²⁹⁸

While the Act does not specifically address conflicts in the interpretation of the form after a patient is incapacitated, a number of provisions suggest that a patient's surrogate has ultimate authority. While the POLST form can only be executed jointly by the physician and surrogate, upon the decision of the patient or surrogate, the surrogate "may revoke a form at any time and in any matter that communicates intent to revoke."²⁹⁹ They may also, at any time, "request alternative treatment that differs from the treatment indicated on the form."³⁰⁰

The statute provides that "any" health care provider, including the patient's physician, emergency medical services personnel and emergency physicians,

must comply with a properly executed and signed POLST form, except in circumstances where the order requests health care that is medically ineffective or contrary to generally accepted health care standards.³⁰¹ The physician is directed to consult with the patient or surrogate before issuing any new orders.³⁰²

5. Oregon

(a) Is there a statutory provision setting out the requirement to obtain informed consent?

In Oregon, capable adults can make their own health care decisions.³⁰³ Like Hawaii, Oregon has statutorily mandated the information that must be provided to patients for consent to be informed:

677.097 Procedure to obtain informed consent of patient. (1) In order to obtain the informed consent of a patient, a physician, podiatric physician and surgeon or physician assistant shall explain the following:

- (a) In general terms the procedure or treatment to be undertaken;
- (b) That there may be alternative procedures or methods of treatment, if any; and
- (c) That there are risks, if any, to the procedure or treatment.

(2) After giving the explanation specified in subsection (1) of this section, the physician, podiatric physician and surgeon or physician assistant shall ask the patient if the patient wants a more detailed explanation. If the patient requests further explanation, the physician, podiatric physician and surgeon or physician assistant shall disclose in substantial detail the procedure, the viable alternatives and the material risks unless to do so would be materially detrimental to the patient. In determining that further explanation would be materially detrimental the physician, podiatric physician and surgeon or physician assistant shall give due consideration to the standards of practice of reasonable medical or podiatric practitioners in the same or a similar community under the same or similar circumstances.³⁰⁴

(b) Is there a statutory mechanism for creating an advance directive?

In Oregon, a capable adult may both execute a health care instruction (a document executed by a principal to indicate the principal's instructions regarding health care decisions) and designate an attorney-in-fact with decision-making power under a power of attorney for health care.³⁰⁵ As set out below, Oregon legislation also contemplates that patients will informally expressing wishes about future care.

(c) What is the legal effect of an advance directive?

The legal effect of a health care instruction is not discussed in broad terms in the Oregon statute. Instead, Oregon legislation provides that advance directives are to be followed by a health care representative in certain circumstances. A health care representative includes an attorney-in-fact.³⁰⁶ The applicable provisions are set out below under the discussion regarding who interprets and applies the advance directive.

(d) Who interprets and applies the advance directive?

In providing guidelines for decision-making, Oregon legislation provides that the health care representative has a duty to act consistently with the desires of the principal as expressed in the advance directive, or as otherwise made known by the principal to the health care representative.³⁰⁷ If the principal's desires are unknown, the health care representative has a duty to act in what the health care representative believes, in good faith, to be the best interests of the

principal.³⁰⁸ To this extent, the health care representative is responsible for interpreting and applying an advance directive.

However, health care providers are instructed to exercise “the same independent medical judgment in following a health care instruction or representative’s decision that the health care provider would exercise in following the decisions of the principal, if the principal were capable.”³⁰⁹ Furthermore, the statutorily mandated form of advance directive incorporated into Oregon legislation provides the following information to patients: “You also have the right to give instructions for health care providers to follow if you become unable to direct your care.”³¹⁰ Also, the Oregon statutory provisions on providing health care to individuals who do not have a relative who can make decisions on their behalf are only applicable where the hospital cannot locate any health care instruction executed by the patient.³¹¹

These statutory provisions strongly suggest that there are circumstances in which the health care provider will take directions directly from the health care instructions in the patient’s advance directive, and thereby interpret it. This view is supported by the fact that Oregon legislation protects health care providers are from liability in certain circumstances for “acting or declining to act in reliance on the health care decision made in an advance directive...”³¹²

(e) Is there a legal distinction between an ‘advance directive’ and other informal expressions of wishes, values and beliefs

Similar to Hawaii, Oregon legislation prioritizes instructions contained in an advance directive. Where a patient has appointed an attorney-in-fact pursuant

to a power of attorney for health care, that health care representative is required to act consistently with instructions in an advance directive or as otherwise made known to the health care representative by the patient. This language suggests that formal and informal health care instructions will both be weighed and considered by the health care representative in making decisions on behalf of the patient.

However, the instructions and protections given to health care providers suggest that advance directives are prioritized over more informally expressed wishes, values, and beliefs. As noted above, health care providers are protected from liability for complying with a health care decision in an advance directive, and are also directed to follow the “same independent medical judgment in following a health care instruction... that the health care provider would exercise in following the decisions of the principal, if the principal were capable.”³¹³ Most importantly, the provisions for providing treatment for a patient without a relative or proxy are only effective where an applicable health care instruction has not been given in an advance directive. There are no equivalent provisions for informally expressed patient wishes. As a practical matter, we understand that health practitioners will often look for a legally recognized surrogate as a result of perceived liability concerns.

(f) Who makes decisions for an incapable patient who has not appointed a proxy?

Where a patient does not have an advance directive and has been medically confirmed to be in one of the following conditions:

- (a) A terminal condition;
- (b) Permanently unconscious;
- (c) A condition in which administration of life-sustaining procedures would not benefit the principal's medical condition and would cause permanent and severe pain; or
- (d) The person has a progressive illness that will be fatal and is in an advanced stage, the person is consistently and permanently unable to communicate by any means, swallow food and water safely, care for the person's self and recognize the person's family and other people, and it is very unlikely that the person's condition will substantially improve,³¹⁴

Oregon legislation provides for a default hierarchy of health care representatives who may direct the withholding or withdrawing of life-sustaining procedures.

For other medical treatments, where there is no health care representative for a patient, there is no other adult relative or adult friend of the patient who is capable of making health care decisions for the patient, and the patient has not executed health care instructions in an advance directive, Oregon legislation provides that a hospital may appoint a health care provider who has received appropriate training in health care ethics to give informed consent to medically necessary health care services.³¹⁵ A hospital ethics committee may also participate in such decisions. In a situation where withdrawal or withholding of a life-sustaining procedure may be permissible, and no authorized health care representative or instruction can be found, the attending physician may direct life-sustaining measures to be withheld or withdrawn.³¹⁶ This is an example of a situation where, at least conceptually, a physician may withdraw treatment in the absence of informed consent from an SDM.

(g) How are disputes resolved?

Oregon legislation permits petitions to the Court to resolve disputes involving advance directives. Specifically, Oregon legislation allows judicial petitions to be brought for:

- (a) Determining whether a principal is incapable.
- (b) Determining whether an appointment of the health care representative or a health care instruction is valid or has been suspended, reinstated, revoked or terminated.
- (c) Determining whether the acts or proposed acts of the health care representative breach any duty of the representative and whether those acts should be enjoined.
- (d) Declaring that an individual is authorized to act as a health care representative.
- (e) Disqualifying the health care representative upon a determination of the court that the health care representative has violated, failed to perform or is unable to perform the duties under ORS 127.535 (4).
- (f) Approving any health care decision that by law requires court approval.
- (g) Determining whether the acts or proposed acts of the health care representative are clearly inconsistent with the desires of the principal as made known to the health care representative, or where the desires of the principal are unknown or unclear, whether the acts or proposed acts of the health care representative are clearly contrary to the best interests of the principal.
- (h) Declaring that a power of attorney for health care is revoked upon a determination by the court that the attorney-in-fact has made a health care decision for the principal that authorized anything illegal. A suspension or revocation of a power of attorney under this paragraph shall be in the discretion of the court.
- (i) Considering any other matter that the court determines needs to be decided for the protection of the principal.³¹⁷

These Court petitions may be made by the patient [principal], the health care representative or the attending physician, among others.³¹⁸

(h) Physicians Orders for Life Sustaining Treatment

Oregon has also implemented a POLST Act.³¹⁹ Unlike Hawaii's POLST Act, which details requirements for a valid POLST form, Oregon's POLST Act is primarily confined to establishing a central registry where POLST forms can be stored, and accessed by health care providers when required. POLST orders are primarily intended for seriously ill patients with life-limiting advanced illness.

The Oregon Medical Board's regulations state that physicians and physicians assistants, as well as certified first-responders or EMTs, shall comply with life-sustaining treatment orders executed by a physician, nurse practitioner or physician assistant,³²⁰ unless there is new information from a patient or appropriate surrogate.³²¹

It is important to note that, under Oregon's POLST statute, valid surrogates can also void a POLST form and request alternative treatment.³²²

6. *Texas*

(a) Is there a statutory provision setting out the requirement to obtain informed consent?

Similar to the other states we reviewed, Texas has statutorily enshrined the requirement to obtain informed consent:

Sec. 74.104. DUTY OF PHYSICIAN OR HEALTH CARE PROVIDER. Before a patient or a person authorized to consent for a patient gives consent to any medical care or surgical procedure that appears on the disclosure panel's list requiring disclosure, the physician or health care provider shall disclose to the patient or person authorized to consent for the patient the risks and hazards involved in that kind of care or procedure. A physician or health care provider shall be considered to have complied with the requirements of this section if disclosure is made as provided in Section 74.105.

...

Sec. 74.105. MANNER OF DISCLOSURE. Consent to medical care that appears on the disclosure panel's list requiring disclosure shall be considered effective under this chapter if it is given in writing, signed by the patient or a person authorized to give the consent and by a competent witness, and if the written consent specifically states the risks and hazards that are involved in the medical care or surgical procedure in the form and to the degree required by the disclosure panel under Section 74.103.³²³

(b) Is there a statutory mechanism for creating an advance directive?

The Texas *Advance Directives Act* creates and distinguishes between three different types of advance directives:

- (1) Medical Power of Attorney: which allows the principal to designate an agent to make decisions on their behalf;
- (2) Directive to Physicians: which functions as a directive for life-sustaining procedures in the event of a terminal or irreversible condition. It also allows for the designation of a decision-maker, where a power of attorney does not exist; and
- (3) Out of Hospital Do Not Resuscitate Orders (OH-DNRs): which create directives with which health care providers, including emergency personnel, are authorised to comply.

The POLST form is not currently recognized in Texas. However, the Out of Hospital DNR Orders addresses some of the same concerns.

(c) What is the legal effect of an advance directive?

Like in Hawaii and Oregon, the legal effect of medical powers of attorney, directives to physicians, and OH-DNRs, is not discussed in broad terms in the Texas statute. Instead, Texas legislation provides the individual circumstances in which advance directives are to be applied. These provisions are set out below.

(d) Who interprets and applies the advance directive?

(i) *Medical Power of attorney*

The Medical Power of Attorney subchapter of the statute provides that a principal's agent under a medical power of attorney may make any health care decision that the principal could make, if competent, subject to the subchapter and any express limitation in the medical power of attorney.³²⁴ The Texas *Advance Directives Act* provides that a "health care provider shall follow a directive of the principal's agent to the extent that it is consistent with the desires of the principal, this subchapter, and the medical power of attorney."³²⁵

In making a health care decision, an agent under a medical power of attorney is directed to first consult with the attending physician and other health care providers, and then make the decision in accordance with the agent's knowledge of the principal's wishes (including religious and moral beliefs) or, where their wishes are unknown, according to the agent's assessment of the principal's best interests.³²⁶

It would appear that, with regard to medical powers of attorney, patient wishes are to be interpreted primarily by the agent, and secondarily by the physician in determining whether the agent is acting in a manner consistent with the instructions of the principal. As would be expected, the Texas medical power of attorney provisions address the designation of a proxy, rather than providing specific instructions for future health care.

(ii) Directive to Physicians

A competent adult has the power to issue a written directive to have life-sustaining treatment administered, withheld or withdrawn in the event of a terminal or irreversible condition, and to appoint a proxy decision-maker or agent under a medical power of attorney.³²⁷ The statute specifies that if a principal has designated a person to make treatment decisions, “the attending physician and the designated person may make a treatment decision in accordance with the declarant’s directions.”³²⁸ If no decision-maker has been authorized, the attending physician shall comply with the instructions unless he or she does not believe that they reflect the principal’s present desire.³²⁹

The meaning of these statutory provisions is confusing, as they seem to provide that decisions about how to implement directives to physicians regarding the withdrawal of life sustaining treatments are to be made jointly by the attending physician and the patient’s representative (unless there is no patient representative in which case the physician shall simply comply with the instructions). To the extent that the legislation appears to envisage a joint decision by the physician and the patient’s representative (or just a decision by physicians) it would appear that both physicians and patient representatives play a role in interpreting and implementing directives to physicians about the withdrawal of life support.

(iii) Out of Hospital Do-Not-Resuscitate Orders

Texas has not recognized the POLST form in statute. However, it has enacted a subchapter on Out of Hospital Do-Not-Resuscitate (OH-DNR) Orders under the *Advance Directives Act*.³³⁰

The OH-DNR order is a legally authorized document prepared and signed by the attending physician that documents the person or authorized decision-maker's instructions, and directs health care professionals acting in an out-of-hospital setting not to initiate or continue life-sustaining treatment involving cardiopulmonary resuscitation, advanced airway management, artificial ventilation, defibrillation, or transcutaneous cardiac pacing. It does not include authorization to withhold medical treatment for comfort care, pain alleviation or treatments that provide water or nutrition.³³¹ It can also be signified by a DNR identification device worn around the wrist or neck.³³²

A physician may rely on a person's previously executed directive as instructions to issue an OH-DNR, and a person designated as a proxy under a directive or an agent under a medical power of attorney may make any decisions required as to an OH-DNR order.³³³

The implementation of an OH-DNR order parallels the 'Directive to Physician' provisions on complying with and executing an OH-DNR for a patient who is incompetent or otherwise mentally or physically incapable of communication. It states that where a directive has been issued it shall be complied with by the physician and authorized decision-maker or, where there is

no authorized decision-maker, it shall be complied with by the physician, unless he or she does not believe that the order reflects the person's present desire.³³⁴

Like the provisions for a directive to physicians, Texas law contemplates that a decision with respect to an OH-DNR will be made both by a physician and the patient's proxy, if available.

(e) Is there a legal distinction between an 'advance directive' and other informal expressions of wishes, values and beliefs?

Interestingly, Texas law appears to not draw a significant distinction between informally and formally expressed wishes. As noted above, where a directive to physicians or OH-DNR has been executed, decisions are made jointly by physicians and SDMs interpreting the advance directive. Where there is no SDM available, directives to physicians and OH-DNRs may be implemented directly by physicians.

Similarly, where a patient has not executed a directive to physicians or OH-DNR, decisions must be made by legal guardians, attorneys, or family members "based on knowledge of what the patient would desire, if known."³³⁵ However, where no other SDM is available, treatment decisions may be made by physicians and/or the hospital ethics committee, again based on knowledge of what the patient would desire.³³⁶

Formal and informal advance directives proceed through the same decision-making process, and appear to be given the same consideration.

Similarly, agents appointed under a medical power of attorney are given the below decision-making instructions:

(e) After consultation with the attending physician and other health care providers, the agent shall make a health care decision:

(1) according to the agent's knowledge of the principal's wishes, including the principal's religious and moral beliefs;
or

(2) if the agent does not know the principal's wishes, according to the agent's assessment of the principal's best interests.³³⁷

Interestingly, agents under medical powers of attorneys are able to make decisions independently “after consultation with attending physicians and other health care providers,” as opposed to other decision-makers who are required to make decisions jointly with physicians. In this way, Texas law appears to prioritize proxies appointed under medical powers of attorney over other SDMs.

(f) Who makes decisions for an incapable patient who has not appointed a proxy?

If there is no authorized decision-maker, the attending physician and at least one qualified relative (spouse, adult child, parent, nearest living relative, in order of priority) may make a treatment decision.³³⁸ If no relatives are available, a second physician not involved with the patient’s treatment, or who is a representative of the facility’s ethics or medical committee, must affirm the decision before treatment can be provided.³³⁹ Treatment decisions may include the decision to withhold or withdraw life-sustaining treatments.³⁴⁰ The Texas statute’s language is notable as it expressly provides a role for the physician in making treatment decisions.

(g) How are disputes resolved?

Unlike other advance directive statutes reviewed, Texas' legislation offers relatively scant provisions on dispute resolution.

There are two different types of dispute resolution in the legislation. First, where a patient has not executed a directive to physicians or OH-DNR, relatives of patients may bring guardianship proceedings to challenge treatment decisions made by SDMs.³⁴¹ This would occur where a family member disagrees with treatment decision made by a higher ranking SDM about the withholding of life-sustaining treatments. Second, the legislation provides that physicians may refuse to comply with directives in certain circumstances (the "Conscience Objection", as discussed above). Where this occurs, the refusal to comply will be subject to review by an ethics or medical committee, during which time life-sustaining treatments will be provided.³⁴²

Texas has not created a specialized tribunal with broader jurisdiction to review disputes relating to health care consent and substitute decision-making.

7. Summary and Commentary on Hawaii, Oregon, and Texas

It is difficult to say with certainty how these three states balanced the policy considerations discussed in this paper in arriving at their particular health care consent and advance care planning legislation. This is partly because the legislation of Hawaii, Oregon, and Texas is somewhat opaque: the legislation clearly anticipates a role for health practitioners in interpreting and giving effect to formalized advance directives in all three states, but is unclear how this is meant

to occur. Texas provides a prime example of this lack of clarity, as the legislation provides that directives to physicians are to be interpreted by both the patient and physician. Similarly, as noted above, Hawaii legislation provides that physicians shall “comply with an individual instruction of the patient, and with a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient.” These statutory provisions do not explain in what circumstances the health practitioner or proxy decision-maker will have primary decision-making authority (if any).

Despite this limitation, it is clear that Hawaii, Oregon and Texas have created a role for formalized advance directives that goes beyond Ontario law, and have placed less of an emphasis on contextualized decision-making by SDMs. What is not clear is whether these jurisdictions have retained any of the practical benefits of this policy – such as efficiencies obtained by not requiring an SDM. Texas appears to have added another layer of complexity - by requiring that certain decisions be made by both the proxy and the health practitioner.

What is also clear is that these jurisdictions have given more authority to health practitioners in making decisions on behalf of incapable patients and in interpreting advance directives. For example, Texas legislation provides that where no default nearest relative is available, decisions can be made by two physicians. Oregon legislation similarly provides that hospitals can appoint a health care provider as an SDM where no other relative is available. In Ontario, such decisions would be sent to the public guardian and trustee.

I. Summary of National and International Review

Of the extra-provincial and international statutes reviewed, the relationship between health care consent and advance care planning in Ontario appears to be unique, or at least close to the far end of a spectrum. While there are elements of Ontario's *HCCA* and *SDA* that are common to many other jurisdictions (such as modified versions of the best interests test), Ontario does not allow prior capable wishes to be given effect without interpretation by an SDM (except in emergencies). While the breadth of decisions that may be covered by an advance directive varies from jurisdiction to jurisdiction, the very broad role of the SDM in Ontario law, and the corollary degree of emphasis on contextualized informed consent appear to be a defining features.

In reviewing these extraterritorial regimes, there are several statutory models that emerge. In Alberta and Nova Scotia, where a patient has executed an advance directive and has also designated an SDM, it is the role of that SDM to interpret and apply the directive (subject to the stipulation that SDMs must apply any applicable direction). In these jurisdictions, it is only where there is no SDM appointed under an advance directive that the health practitioner is able to take direction directly from the document.

British Columbia, Saskatchewan and Queensland go further, and treat an executed advance directive as a decision of the patient upon which the patient's healthcare team may act directly. British Columbia's legislation expressly removes the requirement that a patient must provide informed consent to

treatment for an advance directive to be effective. The wording of the Saskatchewan and Queensland statutes strongly suggests that advance directives will have the same effect as consent to treatment. The Saskatchewan legislation also provides that a physician may simply apply treatment (subject to certain statutory requirements) where no SDM is present.

The English statute goes further still and, where there is no other appointed decision-maker, allows the health practitioner to make a decision in the incapable patient's best interests in the same manner as if the health practitioner were the patient's appointed SDM. The text of the English legislation also suggests that advance directives can be directly implemented by a health practitioner.

All three of the United States jurisdictions reviewed have passed specialized advance directives statutes.

Hawaii, which adopted the *Uniform Health Care Decisions Act* directs health practitioners to "comply with an individual instruction of the patient and with a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient... to the same extent as if the decision had been made by the patient while having capacity."³⁴³ This language suggests that, in Hawaii, a health practitioner may directly implement an advance directive in certain circumstances as an individual instruction of the patient.

In Oregon, a health care representative has all the authority over the principal's health care that the principal would have if not incapable. However, when nobody from the list is willing and available to act as a representative, a hospital may appoint a health care representative to give informed consent to medically necessary health care services. An attending physician may also apparently directly implement an advance directive to withhold or withdraw life-sustaining treatment where no family member or health care representative is available.

Texas falls on the far end of the spectrum, and provides physicians with much broader authority to participate in and make health care decisions. For example, Texas law states that both physicians and the patient's agent or relatives will make health care decisions, and that when the patient's agent or relatives are not present, another physician may fill that role.

We discuss potential reasons for these divergent legislative models below.

J. Why have other jurisdictions taken a different course?

Based on the above review of extra-Ontario legislative models, an interesting question emerges: why is Ontario law unique? As noted above, unlike many other jurisdictions, Ontario has not prioritized wishes, values and beliefs expressed in a formalized 'advance directive' over informally expressed wishes, values, and beliefs. In Ontario, regardless of whether wishes are expressed in a formal written document, or are expressed orally, they are given equal weight. Furthermore, in Ontario the wish will speak to the SDM (except in an emergency)

in giving informed consent to the health practitioner, rather than directly by the health practitioner. This is not the case in many other jurisdictions.

It is beyond the scope of this Paper to explore the history of why each of other jurisdiction adopted the legislative model it did. There are certainly some benefits to legislative schemes addressing decision-making for incapable patients that prioritize formally expressed patient wishes. For example, looking back to the principle of patient autonomy discussed above, prioritizing formally expressed wishes may be seen as more in keeping with a capable patient's right to determine what treatments are administered to his/her own body. In common law systems that enshrine autonomy, why should capable patients not be permitted to forgo contemporaneous informed consent and express a health care wish that 'speaks' directly to the health practitioner in the future?

In her report prepared for Health Canada on advance care planning across the Canadian provinces, Janet Dunbrack noted that there were pros and cons of legislative models involving only "proxy directives" versus those that added "instructional directives." In Ms. Dunbrack's discussion, Ontario's model would involve "proxy directives only", as wishes, values and beliefs cannot be followed by health practitioners without reference to an SDM (except in an emergency).³⁴⁴ These pros and cons provide some insight into why other legislative models have been adopted:

In favour of proxy directives only:

- A proxy directive is flexible and responsive to actual reality because your proxy knows your values. It is almost impossible to create an effective instructional directive because you would have

to predict the future and know what your wishes would be if you became critically ill. Your wishes would probably change as your health condition changed. What would happen if you forgot to update your wishes? Your intimate others and health care providers might be legally bound by outdated wishes. In any case, your values and recent wishes can be expressed to your proxy who will use them as guidance in giving consent to treatment.

- Proxy directives encourage meaningful dialogue with your proxy and family.
- Some physicians find it easier to deal with a written instructional directive instead of dealing with a real person (your proxy). A proxy directive will ensure that your next of kin are consulted by the physician if you lose capacity to give informed consent.
- Instructional directives are hard to interpret and follow. They may use vague terms such as “no heroic measures” or the wishes expressed may be unrealistic.
- People who do not have good relations with their family can appoint a proxy who can stand up to the family; otherwise, the family may take over as substitute decision makers.
- Many health care providers may be treating you. They may all have different interpretations of your instructional directive. Your proxy is the only constant in your care; your proxy can be the advocate who asks that your values and wishes be respected.
- An instructional directive is weaker than a proxy directive or a combination of instructional and proxy directive (where both are recognized in legislation). Without a proxy, you are at the mercy of the system or a conflicted family.

In favour of recognizing instructional directives in legislation:

- Some persons have no family, or no family whom they want to involve in their care. The person may want privacy with respect to their wishes. An instructional directive allows them to have their wishes respected without reference to a substitute decision maker.
- Persons are entitled to choice, autonomy and self-determination. This is a Charter right. Persons should be able to have their wishes respected without the intervention of a proxy or substitute decision maker.

- Seniors want the right to make their own choices and therefore should be able to express their wishes, including wishes that may request no resuscitation in the event of witnessed sudden death (cardiac or respiratory arrest).³⁴⁵

The authors wish to note that we do not endorse the above list as a fulsome and complete statement of the pros and cons of each legislative model.³⁴⁶ However, as set out below, we believe that many of the pros of recognizing instructional directives, set out in the above quote, are also addressed in Ontario's legislation.

We also accept that legislative models, such as British Columbia's, that equate a written advance directive is equivalent to informed consent provide a level of operational simplicity and conceptual clarity for health practitioners (but perhaps not for patients who may not appreciate the effect of such an advance directive). In such jurisdictions, where a wish is contained in a formalized advance directive, the health practitioner may simply comply with the wish if it is applicable – rather than have the health practitioner go through the process of:

- locating the SDM;
- informing the SDM of the formalized wish; and,
- informing the SDM of the requirement to comply with the wish if it is applicable, and if not to act in the patient's best interest.

Two of these three steps could be eliminated by simply allowing the health practitioner to make this determination. Health practitioners are also spared the potential contradictions involved in obtaining voluntary informed consent to treatment from an SDM where the SDM has no true choice: he/she is bound to follow the patient's previously expressed wish. Lastly, this saves health

practitioners from becoming embroiled with battling equally-ranked SDMs where the patient has formally expressed applicable wishes, values, and beliefs.

It may also be seen as preferable to have health practitioners make decisions for patients. The reality of the knowledge imbalance inherent in health care decision-making is that health practitioners will generally have a better sense of the clinical picture that lies ahead than SDMs, and may be better at interpreting specific wishes about particular treatments. Where a patient has expressed a wish applicable to future treatment, why should that wish have to be interpreted by a lay individual who may not be familiar with the patient's health condition or the treatments proposed?

The above is, of course, informed speculation on the considerations other jurisdictions may have balanced in crafting their legislation. We have not reviewed why each jurisdiction passed the legislation that it did. However, we thought it important to explain that we do understand why other jurisdictions have found different solutions to the tension between informed consent and advance care planning. Nevertheless, as set out below, we stand by Ontario law.

K. In support of Ontario law

While there are certainly strengths and weaknesses to each model for resolving the tension between informed consent with advance care planning, the Ontario legislature chose *not* to prioritize formalized advance directives, or to have patient wishes speak directly to health practitioners (except in emergencies). Rather, in order to ensure the authenticity of decision-making for

incapable patients, Ontario law enshrines a role for SDMs as interpreters of prior expressed wishes (in whatever form) and to make decisions about the patients' best interest as part of giving informed consent to treatment.

The Ontario statutory scheme balances informed consent to treatment with the applicability of prior statements made by the patient. To this extent, Ontario law places more of an emphasis on contextualized patient decision-making through informed consent than the other jurisdictions we reviewed. The emphasis placed on contextualized patient decision-making in Ontario is also reflected by the fact that Ontario law limits the ability of patients to consent to future treatments, unless such treatments relate to the patient's current health condition. As noted above, many other jurisdictions have emphasized formally expressed wishes, and have diluted the requirement that informed consent be obtained from a capable individual aware of the risks and benefits of treatment where an 'advance directive' is in place.

In the authors' opinion, Ontario has adopted a more flexible and contextual approach to health care decision-making than other jurisdictions. This model restricts the ability of individuals to consent to future health care decision-making (while balancing this against the right of individuals to express future health care wishes and have them applied in certain circumstances) and also limits the role of health practitioners in directly interpreting and acting upon previously expressed patient wishes (or indeed making other treatment decisions for patients).

Further, this is preferable to the other legislative models we reviewed. Ontario legislation ensures that prior capable wishes are situated in the present health context of the patient as part of the process of giving informed consent to treatment and are interpreted by an SDM of the patient's choosing or a close relative (in many cases). This model best ensures that authentic decisions are made by SDMs for incapable patients, by requiring that patient wishes are checked against the risks and benefits of treatments proposed.

Other legislative models that give more authority to health practitioners, and that allow patients to pre-select treatments, risk losing a fundamental feature of health-care decision-making – informed consent. Rather than either removing the requirement to obtain informed consent when giving effect to 'advance directives', or requiring that SDMs make purely independent decisions, Ontario's legislation provides a balance. Prior wishes are contextualized in the patient's current health condition and the treatment information provided by the health practitioner. Where the wishes are still applicable, they are binding on the SDM. Where they are not applicable, the SDM is not bound by an uninformed choice.

Importantly, the Ontario legislative model also protects health practitioners. As the Fram Report noted, "providers of services should not be asked to determine the value of their services to the life of an individual."³⁴⁷ The role of the health practitioner is to obtain an informed consent. Where the patient is incapable, the health practitioner is provided with the clarity and simplicity of a default list of SDMs who may give consent on the patient's behalf. The *HCCA*

protects health practitioners from liability where they act reasonably and in good faith.³⁴⁸

VI. APPLICATION OF THE LAW OF HEALTH CARE CONSENT AND ADVANCE CARE PLANNING IN ONTARIO

A. Review of Regulatory Policies and Publications³⁴⁹

1. College of Physicians and Surgeons of Ontario (CPSO)

The CPSO is the organization tasked with regulating physicians in Ontario. The CPSO has prepared numerous policy documents to provide guidance to physicians, and which can be enforced through the CPSO's internal disciplinary and quality assurance processes.

We located two policies that are relevant to this research project: *Consent to Medical Treatment*, Policy 4-05³⁵⁰ and *Decision-making for the End of Life*, Policy 1-06.³⁵¹

The CPSO policy on *Consent to Medical Treatment* sets out the general law on consent to treatment, providing care in emergencies, and capacity to make health care decisions (including the rights information that must be provided to persons found incapable with respect to treatment). As a plain language explanation of Ontario law, there are no significant issues with this policy that are relevant to this research project.³⁵²

The CPSO Policy on *Decision-making for the End of Life* (the "End of Life Policy") was prepared to "assist physicians in providing medically and ethically appropriate care to patients at the end of life."³⁵³ The majority of this policy appropriately focuses on the patient's right to consent to treatment. In its section on "Advance Care Planning," the End of Life Policy provides that "patient's advance care instructions and wishes are reassessed with the patients or

substitute decision-makers, and family if there is consent, on an ongoing basis”

[emphasis added].³⁵⁴ Later, in discussing whether CPR and other life-sustaining treatments should be proposed, the Policy states:

Physicians should recognize that decisions concerning resuscitation and other life-sustaining treatments might change over time. These decisions should be reassessed whenever it is appropriate to do so; in particular, when the condition of the patient changes and when the patient or substitute decision-maker indicates that he or she has changed the decision about such treatment. [Emphasis added]³⁵⁵

In short, physicians are reminded to continually communicate with patients or their SDMs and family, if there is consent, as the patient’s condition changes. This reminds physicians that just because a patient or an SDM has given an informed consent to treatment or a plan of treatment that the physician is not locked into that decision when the patient’s condition has changed. However, as this paragraph is under the section on “Advance Care Planning” and refers to re-assessing advance care plan “wishes”, this may lead physicians to confuse advance care plan wishes (which must always be given by a capable patient, never by an SDM) with informed consent for a proposed treatment (given by either a capable patient or his/her SDM). It appears to suggest that SDMs can advance care plan on behalf of incapable patients by expressing new wishes or altering previously expressed wishes, values and beliefs.

As a more general comment, the Policy does not draw a distinction between different types of end of life communications and decisions, such as:

- (a) expressions of “wishes” by the patient;
- (b) recounting of prior patient “wishes” for future treatment by the SDM to the treating team;

(c) expressions of new wishes for future treatment (i.e. wishes not previously expressed by the patient) by the SDM (which are of no legal effect); and,

(d) consent to a “plan of treatment” for future treatments by either the patient or, if incapable, their SDM.

The legal effect of each of the above items is different (or non-existent) under Ontario law. For example, while an SDM can recount prior expressed wishes of a patient to a treating health care team to be relied upon in an emergency (and in assessing whether the SDM is complying with his/her obligations under the *HCCA*), any expression of new wishes by the SDM cannot be given legal effect. However, an SDM is able to give or refuse consent to a plan of treatment governing future care, provided that this plan of treatment complies with the requirements in the *HCCA* (e.g. the plan of treatment is contextualized in the patient’s current health condition and informed consent is obtained). As a guidance document, the End of Life Policy should be clear that physicians cannot give effect to new wishes expressed by SDMs, that an SDM’s primary role is to give or refuse consent and not advance care plan for the incapable patient, and should distinguish between consent to treatment and advance care planning through soliciting patient wishes.

Similarly, in its discussion of the role of the physician in determining whether CPR and other life-sustaining treatments will be provided to a patient, the Policy suggests that physicians should consider a patient’s goals, values and beliefs in determining whether to propose CPR and other potentially life-

sustaining treatments.³⁵⁶ The problem with this suggestion is that, under the *HCCA*, the task of interpreting a patient's wishes, values and beliefs is left to the patient's SDM. This policy, if read to suggest that physicians should pre-screen the treatments proposed for incapable patients based on their interpretation of the patient's wishes, values and beliefs, could inadvertently lead to the statutory role of the SDM being bypassed.

In the authors' view, the *HCCA* creates a statutory role for the SDM as the interpreter of an incapable patient's wishes, values, and beliefs at first instance. The SDM's role is to contextualize the patient's wishes, values and beliefs, based on the patient's then current health condition and the information provided by the patient's physicians. In order to fulfill this role, SDMs must obtain complete information from health practitioners about proposed treatment options. In our view, the *HCCA* would not permit pre-screening treatments proposed to the SDM based on the health practitioner's interpretation of prior expressed wishes of the patient. The End of Life Policy should be clarified to reflect this fact.

2. Canadian Medical Protective Association (CMPA)

The CMPA is a national organization that provides medico-legal liability protection and advice for physicians. Almost every physician in Canada is a member of the CMPA. The CMPA makes a variety of educational materials available on its website. As part of this research project, we located three documents to be reviewed: an article entitled "End-of-Life care – Support, comfort, and challenging decisions"³⁵⁷ a document entitled *Consent: A Guide for*

Canadian Physicians,³⁵⁸ and relevant passages from the *Medico-Legal Handbook for Physicians in Canada*.³⁵⁹

The article entitled “End-of-Life care – Support, comfort, and challenging decisions” states that it is written by physicians for physicians, and that one of the purposes of this document is to provide guidance for physicians faced with difficult clinical situations. Under the heading “Advance Directives” the article provides as follows:

The healthcare provider may wish to defer taking direction from the document, particularly where there is any uncertainty, without first speaking to the patient (if capable) or the substitute decision-maker. Advance directives are to be interpreted by the patient’s substitute decision-maker. The substitute decision-maker is generally obligated to follow these directions, unless he or she has knowledge of the patient’s other express wishes...³⁶⁰

The opening sentence is potentially problematic in Ontario, because unless an advance directive meets the test for consent to a plan of treatment, it cannot be acted upon directly (except in an emergency), and must always be interpreted by the patient’s SDM. While the above passage correctly notes that advance directives must be interpreted by an SDM, it suggests that in some circumstances (without specifying what these may be) a physician may act upon an advance directive without first consulting an SDM.

This passage could also be interpreted as suggesting that a physician may act on an advance directive for a capable patient. If a patient is capable, under Ontario law the physician must never rely on an advance directive (unless it is an emergency and the capable patient cannot communicate). The health practitioner must instead speak directly with the patient to obtain consent. This

article could be improved by drawing a distinction between wishes, values and beliefs, and distinguishing between consent to future treatments and advance care planning through expressing wishes, values and beliefs.

In fairness, we should note that this is a national document that expressly states it is not providing medical or legal advice and recommends that physicians should be generally familiar with an applicable legislation in their particular jurisdiction. However, it may contribute to some of the confusion around health care consent and advance care planning we have identified in this Paper.

Both the document entitled “End-of-Life care – Support, comfort, and challenging decisions” and the document entitled *Medico-Legal Handbook for Physicians in Canada* contain a nearly identical version of the following passage (the below is from the *Handbook*):

While it is undisputed that a physician must respect any known wishes of a patient not to receive a particular procedure or treatment, it is less clear whether a patient (or the appropriate substitute decision-maker) has a positive right to demand that a specific form of treatment be given, even though the physician may disagree.³⁶¹

The first clause in the above sentence is worthy of comment. This clause could be interpreted as stating that a physician must, in all circumstances, respect any known wishes of the patient. This is not a complete statement of Ontario law. In Ontario, it is the responsibility of the patient’s SDM to consider known wishes to determine whether they are applicable and must be followed, except in an emergency. Immediately following the above quote, the *Handbook* goes further and states:

However, recent case law demonstrates a trend to give greater weight to the views of the patient and the substitute decision-maker (usually the family) regarding end-of-life decisions. Thus, for example, cultural and religious considerations of the family may well influence treatment decisions, or at least the timing of the same.³⁶²

The problem with this additional passage is that it appears to apply to both treatments proposed by the physician and treatments not proposed but requested by the patient's SDM. For treatments proposed to the SDM by a physician, it is potentially misleading to state that the "views" of the SDM are given "weight". Subject to an application to the CCB, the SDM decides whether proposed treatments will be provided to the patient. This paragraph could be improved by drawing a distinction between input by the patient and SDM into which treatments a physician should propose for the patient (a decision that is ultimately the physician's to make), and the patient or SDM's choice of which proposed treatments to consent to.

Similarly, both the *Medico Legal Handbook for Physicians in Canada*, and *Consent: A Guide for Canadian Physicians* contain the below statements that could contribute to physicians misinterpreting Ontario law:

Medico Legal Handbook for Physicians in Canada

Legislation exists in most provinces and territories that specifically empowers a patient to execute an advance directive as to future care in the event the patient later becomes incapacitated or unable to communicate such wishes. An advance directive may contain explicit instructions relating to consent or refusal of treatment in specified circumstances, sometimes referred to as a living will.³⁶³ [Emphasis added]

Consent: A Guide for Canadian Physicians

It is now possible in the majority of provinces for a patient to execute an Advance Directive as to future care in the event that the patient becomes incapacitated or is unable to communicate his or her wishes. Advance Directives are sometimes referred to as living wills. Advance Directives may contain explicit instructions relating to consent or refusal of treatment in specified circumstances.... Again, physicians will want to be generally familiar with any applicable legislation in their particular jurisdiction.

...

In the absence of a valid Advance Directive or duly authorized substitute decision-maker, strictly speaking only the court or someone appointed by the court may properly consent to or refuse medical treatment where the patient lacks the requisite capacity to make the decision. Unfortunately, the legal procedure for the appointment of a guardian of the patient can be lengthy and expensive. As a result, and from a practical standpoint, physicians have often proceeded on the basis of the family's approval where the medical treatment is clearly required, where the patient's condition may deteriorate if not treated promptly, and the treatment is determined to be in the patient's best interests...³⁶⁴ [Emphasis added]

Both of the above passages, but particularly the *Medico Legal Handbook for Physicians in Canada*, suggest that there is consensus (or near consensus) among Canadian provinces on the effect of an advance directive. However, the effect of an advance directive varies significantly across Canada, particularly when compared with Ontario. The quoted passages' use of the language "advance directive" and "explicit instructions," which could be misinterpreted to mean that an advance directive is an instruction directly to the physician.

More importantly, *Consent: A Guide for Canadian Physicians* equates the effect of an advance directive with a consent from an SDM, suggesting that a physician need not obtain substitute consent where he/she has obtained a valid advance directive. As an explanation of Ontario law, this is incomplete, and potentially incorrect.

Lastly, *Consent: A Guide for Canadian Physicians* uses the phrase “duly authorized decision-maker,” which could be misinterpreted as meaning that an SDM must take an active step in order to be authorized to act, which is not correct in Ontario if the SDM is a family member listed in the hierarchy set out in the *HCCA*. As described below, this is a common misconception that arose in our focus groups.

3. *Canadian Medical Association (CMA)*

The CMA is a national organization with a voluntary membership that advocates on behalf of physicians. The CMA has two policy documents that are relevant to this Paper: a joint policy statement with other health organizations entitled *Joint Statement on Resuscitative Interventions*,³⁶⁵ and a policy entitled *Advance Directives for Resuscitation and other Life-Saving or Sustaining Measures*.³⁶⁶

Both policies could be construed as suggesting that physicians should interpret a patient’s prior wishes in deciding upon treatment options, and do not mention the role of the SDM in interpreting these prior wishes. Below are the relevant passages from the *Joint Statement on Resuscitative Interventions* and *Advance Directives for Resuscitation and other Life-Saving or Sustaining Measures*, respectively:

Joint Statement on Resuscitative Interventions

4. When a person is incompetent, treatment decisions must be based on his or her wishes, if these are known. The person's decision may be found in an advance directive or may have been communicated to the physician, other members of the health care team or other relevant

people. In some jurisdictions, legislation specifically addresses the issue of decision making concerning medical treatment for incompetent people; the legislative requirements should be followed.

5. When an incompetent person's wishes are not known, treatment decisions must be based on the person's best interests, taking into account:
 - (a) the person's known values and preferences;
 - (b) information received from those who are significant in the person's life and who could help in determining his or her best interests;
 - (c) aspects of the person's culture and religion that would influence a treatment decision;
 - (d) and the person's diagnosis and prognosis.

In some jurisdictions legislation specifies who should be recognized as designated decision-makers (proxies) for incompetent people; this legislation should be followed. The term "proxy" is used broadly to identify those people who make a treatment decision based on the decision a person would have made for himself or herself (substitute decision-maker), people who help in determining what decision would be in the person's best interest and people whose appropriateness to make treatment decisions for the person is recognized under provincial legislation.³⁶⁷

Advance Directives for Resuscitation and other Life-Saving or Sustaining Measures

Some people want to specify in advance the types of medical procedures they would or would not want to undergo in the event that they become incompetent. They can fulfil this desire through a written advance directive, or by appointing a proxy decision-maker, or both. Physicians should assist their patients in these endeavours. They should honour a patient's advance directive unless there are reasonable grounds for not going so.

...

Patients frequently believe that an advance directive to refuse life-saving or sustaining measures will be honoured under all circumstances. The reality of medical practice makes this impossible. If an advance directive is specific to a particular set of circumstances the directive itself will have no force when these circumstances or ones essentially similar to them do

not exist. On the other hand, if an advance directive is so general that it applies to all possible circumstances that could arise it is usually too vague to give any usable direction to the physician. In either case physicians will have to rely on their professional judgement to reach a decision.

...

1. A physician should assist a patient in a consultative capacity in the preparation of an advance directive concerning life-saving or sustaining measures if the patient requests such assistance. In the course of this consultative process, the physician should try to make sure that the patient understands the limits of such documents. Also, the physician should impress upon the patient the need to make advance directives reasonable and accessible. Any such advance directive should be in writing.³⁶⁸ [Emphasis added]

While the *Joint Statement* appropriately recognizes the role of the SDM for an incapable patient where no wishes are expressed (see item #5 of the above excerpt), it does not reinforce for physicians that the SDM is the primary interpreter of an incapable patient's prior expressed wishes (see item #4 of the above excerpt). Furthermore, the *Joint Statement* provides that decisions about CPR should be reviewed when a proxy "changes his or her decision about resuscitation."³⁶⁹ This could be interpreted as suggesting that SDMs are able to express legally binding new wishes on behalf of patients, which is not the law in Ontario. However, it could also be interpreted as referring to consent to a treatment decision about resuscitation. The *Joint Statement* should draw a distinction between consent to treatment obtained from the SDM (which is permitted under the *HCCA*), and the expression of new wishes on behalf of patients (which is not).

In the above quote, the *Advance Directives for Resuscitation* document suggests that physicians must honour advance directives and will have to rely on

their professional judgment in interpreting advance directives. While this is true of emergencies, this is an incomplete statement with regard to treatment generally - where the task of interpreting advance directives and determining whether to honour an advance directive falls, at least at first instance, on the SDM. The text of the policy on *Advance Directives for Resuscitation* should distinguish between the role of the SDM in interpreting prior capable wishes, and the role of the physician in ensuring that SDMs are complying with their legal obligations.

The policy on *Advance Directives for Resuscitation* suggests that advance directives must be in writing in order to be given effect (which is not true in Ontario). More broadly, the policy on *Advance Directives for Resuscitation* uses the language of “advance directives” rather than wishes, values and beliefs, which may contribute to some of the misconceptions noted below on the legal effect of advance care planning. This policy could be improved by more closely tracking the language of the *HCCA*.

Both policies, while understandably general in nature, could be improved by providing more detail on the law of Ontario. While these documents refer to emergency treatments (such as CPR), where physicians may withhold treatment in an emergency based on their understanding of a patient’s prior expressed wishes, they do not clearly state that they are only applicable to emergencies. The CMA policy on *Advance Directives for Resuscitation* specifically refers to medical interventions beyond resuscitation, and so could be interpreted as applying beyond emergencies as defined in the *HCCA*. The distinction between

emergency and non-emergency treatment should be clarified in both CMA policies.

In fairness, we note that both documents predate the implementation of the *HCCA*. However, these documents remain available on the CMA website as applicable to advance directives and resuscitative intervention.³⁷⁰ Given their age, it may be time to revisit these policies with a particular focus on Ontario law.

4. College of Nurses of Ontario (CNO)

As part of this research project, we reviewed the CNO policies on *Consent*³⁷¹ and *Guiding Decisions About End-Of-Life Care, 2009*.³⁷² No significant issues were identified with either of these documents that are relevant to this paper. Indeed, the policy on *Guiding Decision About End-Of-Life Care, 2009* appropriately distinguishes between consent to a plan of treatment and prior capable wishes, and also uses much of the language of the *HCCA*.

We note that the policy entitled *Guiding Decisions About End-Of-Life Care, 2009* could be improved by avoiding the language of “advance directives” and instead focusing on patient wishes, values and beliefs. This is an issue that is common to almost every document reviewed.

5. Ian Anderson Continuing Education Program in End-of-Life Care

The Ian Anderson Continuing Education program is a joint project of the Faculty of Medicine at the University of Toronto, the Joint Centre for Bioethics at the University of Toronto, and the Temmy Latner Centre for Palliative Care at

Mount Sinai Hospital in Toronto. The goal of this project is to “educate 10,000 primary care physicians and specialists across Canada over a five-year period to deal with issues surrounding death and dying.”³⁷³ As part of this project, numerous education modules have been prepared and, for the purposes of this Paper, we reviewed Module 4 entitled “End-of-Life Decision Making” (the “Module”).³⁷⁴ We should note that, as an appendix to the Module, the Ian Anderson Continuing Education Program attaches a paper by ACE staff entitled: “Health Care Consent, Substitute Decisions and Advance Care Planning – The Law in Ontario.”³⁷⁵

In general, the material contained in the Module is impressive. It is clear that the authors of the Module recognized the need to contextualize end-of-life decision-making in the current health condition of the patient. The Module also contains good plain language explanations of common end-of-life medical interventions.³⁷⁶ Importantly, the Module contains a provision on consent to treatment, noting:

Consent

- Patients have the right to make decisions about their medical treatments and care even at the end of life.
- If a person is capable consent to treatments should be obtained from him/her. If a person is incapable, consent must be obtained from the substitute decision-maker.
- When a person is nearing the end of his/her life, it is important that physicians place all discussions and consent for treatments in context of how these treatments will affect the patient’s remaining quality of life, whether they will prolong life and whether the benefits of such treatments outweigh their burdens and discomfort.

- Obtaining consent for treatments or procedures should not be used to avoid discussing and confronting the larger issues of death and dying and the remaining hopes and goals of patients. Treatments should always be considered based on their ability to increase the likelihood of achieving goals that the patient deems worthwhile.³⁷⁷

While the Module has much to recommend it, it could be improved by integrating the full legal context of health care consent and advance care planning into its educational program for physicians on best practices for communicating with patients. The Module largely leaves the discussion of the legal context of the role of the SDM and the legal effect of ‘advance directives’ to the legal paper contained as an appendix. The authors’ concern with this approach, which is not unique to the Module, is that it separates the ‘law’ from the recommended practice. As physicians are largely responsible for advising SDMs of their important role in effecting the patient’s wishes, values and beliefs, it would be preferable to directly incorporate the legal best practices into the medical guidelines on communicating with patients and their families. The appendix legal paper to the Module, prepared by ACE, notes that the law and practice should not be separate:

The law is the framework in which physicians and patients and their substitutes address end-of-life care. The law is not “separate” from the process that takes place. The End-of-Life Decision-Making module describes what needs to be considered in providing good end-of-life care. Much of what is described in this module is “the law” although not so identified as such (i.e., the need to get consent from a patient or a substitute if the patient is not capable, the determination of capacity, the role of advance planning). This section more specifically describes the law that applies to health care consent, substitute decisions, and advance care planning in Ontario. It follows the order of the module and uses the same section headings to assist in relating the law to the appropriate section in the module.³⁷⁸

Like the other documents we reviewed, the Module also contains statements that could be misinterpreted and thereby contribute to some of the misconceptions we identify below:

If a dying person is no longer capable of making health care decisions, good advance care planning would mean that their substitute decision-maker or their written advance directive would be able to guide decisions in view of their previously expressed wishes, values and beliefs.

...

Advance care planning is a process whereby the patient, with the help of his/her health care providers, family members and loved ones, makes decisions about his/her future medical care.³⁷⁹ [Emphasis added]

The first quoted paragraph equates consent from an SDM with a written advance directive, suggesting that where a patient has an advance directive the health practitioner may simply act upon that document. While this statement would be true if confined to emergencies, it is not a correct statement of Ontario law generally. The second quote paragraph uses the language of “decisions” to refer to advance care planning, which could be misinterpreted to mean that the patient is expressing something beyond wishes. Like many of the other documents reviewed, the Module could be improved by using language that more closely aligns with the *HCCA*.

We should also note that the Module appears to be no longer offered post May 1, 2007.³⁸⁰ Given recent developments in the law, we would suggest that this Module be revisited. The same is true of the paper prepared by ACE and appended to the Module. Since preparing the paper appended to the Module, we have watched the practice in Ontario develop, which has refocused our analysis

of health care consent and advance care planning in Ontario as reflected in this Paper.

The Module also refers physicians to other resources, such as “Let Me Decide” (critiqued below).³⁸¹ These resources may contribute to some of the misconceptions around Ontario law identified in our focus groups and should be reviewed to determine whether they should still be recommended.

6. Educating Future Physicians in Palliative and End-of-life Care (EFPPEC)

The EFPPEC project has developed curriculum materials to be used by “formal caregivers and undergraduate and postgraduate students in the health professionals [*sic*]”³⁸² In preparing this report, the authors’ reviewed a document entitled “Facilitating Advance Care Planning: An Interprofessional Program” (the “Curriculum Materials”),³⁸³ which we understand is generally used to train physicians across Canada. We should acknowledge that ACE was consulted during the preparation of these materials, but did not have editorial control.³⁸⁴

While the Curriculum Materials generally do not explain the law in any specific Canadian province, they do highlight for physicians many of the common pitfalls that have been identified in this Paper. Specifically, the Curriculum Materials note that:

Consent to treatment must be obtained from a capable adult. The fact that the person has an advance directive or has appointed a substitute decision-maker is NOT relevant as long as the person is capable of making his or her own decisions about care.

If an individual becomes mentally incapable of making health care decisions and has left prior instructions or wishes about care in the event of incapacity, documented in an advance directive or in the medical

record, those instructions or wishes may not provide consent to or refusal of treatment. Health care providers must be familiar with the legal requirements for obtaining consent to treatment of incapable persons.³⁸⁵

Later, the Curriculum Materials contain a chapter on consent to treatment which addresses the relationship between consent to treatment and advance care planning and states:

Several provinces give the responsibility of giving or refusing consent to treatment for an incapable person to the person's substitute decision-maker, who must make decisions that the substitute decision-maker believes the incapable person would likely have made if capable or must follow the person's wishes as set out in an advance directive. In the above example, after discussion with the person's physicians about the hope for recovery, the substitute decision-maker would have the legal right to give or withhold consent to dialysis to the physicians, but would have to follow the patient's previously expressed wish to refuse consent to dialysis if the physicians believe there is no reasonable hope for recovery.

Other provinces provide for an advance directive that speaks directly to the health care provider about the person's prior decisions about treatments that he or she would accept or refuse if incapable. Such directives may be used as consent to provide or withhold treatment. If provincial or territorial law enables people to make treatment "decisions" in advance, there would be a legal obligation on the health care provider's part to ensure that the person had the specific information necessary to understand and appreciate the consequences of the decisions being expressed in the advance directive—the same information that a capable person would need for a valid consent. It is arguable whether or not the same requirement applies to just expressing "wishes" about care in advance.³⁸⁶

While it would be preferable for the Curriculum Materials to go into a more in-depth discussion of the law of each province, it is good that future physicians are advised to be aware of this particular legal issue.

While the Curriculum Materials contain many positive features, we nevertheless believe that they may contribute to some of the misconceptions

around health care consent and advance care planning identified in this paper.

Specifically, the Curriculum Materials:

- use the language of instructions and decisions, in addition to the language of wishes (suggesting that such instructions and decisions speak directly to health practitioners);³⁸⁷
- conflate advance care planning through the expression of wishes, values and beliefs with informed consent to a plan of treatment. Specifically, the Curriculum Materials appear to treat consent to a plan of treatment as part of advance care planning;³⁸⁸ and,
- prioritize written advance care planning by emphasizing that physicians inquire whether patients have an “advance directive”.³⁸⁹

These materials could be improved by specifically tracking the language in the *HCCA* and distinguishing between consent to future health care and the expression of wishes, values and beliefs.

B. Review of Consent and Advance Care Planning Forms and Systems³⁹⁰

1. Resident Assessment Instrument (RAI) RAI MDS 2.0 Canadian Version

The Resident Assessment Instrument - Minimum Data Set (RAI MDS) is a tool originally developed in the United States for the standardized evaluation of the needs, strengths, and preferences of persons residing in nursing home institutional settings.³⁹¹ The Ontario Ministry of Health and Long-Term Care mandates use of the Canadian version of the RAI MDS in Ontario long-term care homes.³⁹² In preparing this Paper, we reviewed the *Resident Assessment Instrument (RAI) RAI-MDS 2.0 User's Manual, Canadian Version*³⁹³ (the “*User's Manual*”) currently in use in long-term care homes throughout Ontario.

The *User's Manual* contains numerous assessment forms and tools that are to be completed by health practitioners at long-term care homes. The “Full Assessment” form specifically provides a coding box in which a health practitioner can record whether a patient has an “Advance Directive.”³⁹⁴ The *User's Manual* explains the purpose and impact of recording this information, and states:

A12 Advance Directives

Intent

To determine whether the person has provided guidelines for how care should be rendered in the event that he or she becomes unable to communicate this information. To record the legal existence of directives regarding treatment options for the person, whether made by the person or a legal proxy. Documentation must be available in the record for a directive to be considered current and binding. The absence of pre-existing directives for the person should prompt discussion by clinical staff with the person and family regarding the person's wishes. Any discrepancies between the person's current stated wishes and what is written in legal documents in the person's file should be resolved immediately.

Definition

A12a. Advance directives for not resuscitating—In the event of respiratory or cardiac failure, the person, family or legal guardian has directed that no cardiopulmonary resuscitation (CPR) or other life-saving methods will be used to attempt to restore the person's respiratory or circulatory function.

A12b. Advance directives for not hospitalizing—A document specifying that the person is not to be hospitalized even after developing a medical condition that usually requires hospitalization.

Process

Ask the person or family about whether advance directives have been specified. In order for a directive to be considered current and binding, there must be documentation in the person's record in accordance with relevant provincial/territorial law. Do not code the item unless such documentation is present.

Coding

Code for the appropriate response.

0 Not in place
1 In place³⁹⁵

[Emphasis Added]

As seen in the underlined passages, the *User's Manual* could be interpreted as suggesting that SDMs may express new wishes on behalf of patients, and then further suggests that an advance directive can be “current and binding” (while still referring the health practitioner to “relevant provincial/territorial law” in relation to the documentation of an advance directive). The statement that an advance directive can be “current and binding” suggests that advance directives may be acted upon directly by health practitioners, rather than be interpreted by an SDM.

Similarly, the reference to *documented* advance directives as “current and binding”, and the reference to “what is written in legal documents” could be interpreted as suggesting that:

- advance directives are only given effect when they are in writing;
- a written advance directive takes priority over later oral expression of capable wishes by the patient;
- an advance directive can be applied directly by a health practitioner without consent by the patient or SDM; and,
- an advance directive is only binding when it is current.

All of these interpretations are incorrect, or are significantly incomplete, as expressions of Ontario law.

The *User's Manual* could also be interpreted as confusing informed consent and advance care planning. While the *User's Manual* discusses directives about CPR through the rubric of advance care planning, for many

patients refusals of CPR are addressed and documented through the process of informed consent to a plan of treatment. Similarly, the *User's Manual* refers to directions about CPR being given by the “person, family or legal guardian”, when these SDMs cannot express new wishes on behalf of patients (but can only give informed consent). This could cause health practitioners to confuse the legal role of informed consent with the legal role of advance care planning.

The *User's Manual* (and its form) could be improved by engaging with issues of health care consent and the legal effect of advance directives. Specifically, we would encourage the *User's Manual* to distinguish between consent to treatment and expressions of wishes, values and beliefs, and to apprise health practitioners about the common pitfalls identified in this Paper.

The authors are particularly concerned about the *User's Manual* because we have been advised by some health practitioners practicing in long-term care homes that, because the Canadian version of the RAI MDS is mandated for use in Ontario long-term care homes, they believe they are required to obtain a written advance directive from all residents. This is incorrect, as no patient can be compelled to advance care plan (and especially not through a particular template).

2. Canadian Hospice and Palliative Care “Speak Up”

The Canadian Hospice Palliative Care Association (CHPCA) has developed several advance care planning toolkits and workbooks to encourage patients to begin expressing wishes, values, and beliefs in the event they

become incapable of giving or refusing consent on their own behalf. These programs and toolkits are entitled “Speak Up”. The CHPCA offers both national and Ontario-specific resources.³⁹⁶ While the CHPCA initially prepared a national workbook, the Ontario Alzheimer Knowledge Exchange Health Care Consent and Advance Care Planning Community of Practice adapted this national workbook to better reflect Ontario law. The CHPCA approved an Ontario specific version of the workbook and agreed to offer it in addition to the national workbook.

While we reviewed many of the materials available on the “Speak Up” website, we focussed our analysis primarily on the *Advance Care Planning Workbook, Ontario Edition* (the “*Workbook*”).³⁹⁷ The *Workbook* has been widely distributed in Ontario, and is being relied upon by members of the public and health practitioners.

The goal of the *Workbook* is to encourage members of the public to begin discussing their wishes values, and beliefs for future health care with their family, friends and family doctor. The *Workbook* provides some guidance to patients on typical advance care planning scenarios, tips for beginning difficult conversations with SDMs, information on the legal framework in Ontario, and contains a blank advance care planning form that can be completed by the general public.

The *Workbook* correctly identifies the role of advance care planning under the *HCCA* and explains that the purpose of advance care planning documentation is to provide guidance to SDMs. However, we do believe the

contents of the *Workbook* could be improved to give greater value to the patient wishes, values and beliefs expressed with its assistance. The *Workbook* encourages patients to express very specific health care wishes and could be improved by placing more of an emphasis on contextualizing those wishes in the patient's present health condition. It could also be improved by adding a better explanation of the medical interventions that are being refused or accepted. While bearing these critiques in mind, we should note that much of the information contained in the *Workbook* is helpful, and our suggestions relate more fundamentally to the trend we have observed in Ontario of encouraging advance care planning in a factual vacuum and separated from engagement with informed consent to treatment.

The *Workbook* contains the following passage explaining to patients how they should begin to think and express wishes about future health care options:

1. Think about what is right for you

Begin by reflecting on your values, beliefs and understanding about end-of-life care or specific medical procedures, such as drug therapies, cardiopulmonary resuscitation (CPR) or dialysis. Think about any situations that you may have experienced with others and how it made you feel. You should also speak with your health care providers to ensure you have accurate information about your own health condition in order to express wishes about medical procedures that you may or may not want.

Ask yourself:

- If possible, would I prefer to die at home, in a hospice or in the hospital?
- What might change my mind about my choice?
- Do I want or not want certain medical interventions (e.g., resuscitation or feeding tubes) if I am unlikely to survive or live independently?
- Why would I want or not want these procedures?

- Do I have any fears about dying (e.g., I'll be in pain, I won't be able to breathe)?
- Is there someone that I can talk to about these fears, such as my doctor?
- What would be meaningful for me at the time of my death (e.g., family/friends nearby, music playing or pictures)?

2. Learn about end-of-life care options and procedures

Some individuals want to prolong life as long as possible using medical interventions. Others would not want to be hooked up to machines at the end of life if there is no chance of recovery.

We have included a list of Advance Care Planning terms and medical procedures on pages 13 and 14 to help you consider what is right for you.³⁹⁸

The *Workbook* goes on to describe and define common end-of-life medical interventions:

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that may restart the heart and machines that breathe for the individual.

Comfort measures are treatments to keep you comfortable (e.g., pain relievers, psychological support, physical care and oxygen).

Dialysis is a medical procedure that cleans your blood when your kidneys can no longer do so.

...

A **feeding tube** is a way to feed someone who can no longer swallow food.

...

Intravenous (IV) is a way to give you fluids or medicine through a vein in your hand or another part of your body.

...

A **ventilator** is a machine that helps people breathe when they cannot breathe on their own.³⁹⁹

The authors' difficulty with the above quote is not that it is incorrect, but that it could inadvertently lead to low-quality and uninformed, yet very specific,

expressions of prior capable wishes. Encouraging the general public to express wishes about dialysis, mechanical ventilation, and CPR in the abstract raises concerns that, when SDMs are called upon to provide informed consent, they either will be or will believe themselves to be bound by an uninformed wish.

In our view, in order to express a useful wish to receive or reject a feeding tube, a patient should at least be aware that this would involve the placement of a tube in the nose or abdomen. Similarly, it is difficult to imagine that a patient could express a robust wish about CPR without being aware that chest compressions may result in numerous broken ribs. Yet, the *Workbook* asks the public to give these specific directions absent this knowledge. To be fair, it may be that documents such as this are part of a broader strategy to initiate a more fulsome discussion but, if used in isolation, they may not provide sufficient information to make an informed wish.

The limitations of the above glossary terms become more apparent when compared with the recommended explanations of end-of-life treatments contained in the Ian Anderson Module on End-of-Life Decision-Making and the EFPPEC Curriculum Materials, discussed above. For example, while the *Workbook* states that a ventilator “is a machine that helps people breathe when they cannot breathe on their own”,⁴⁰⁰ the Module provides the following suggested explanation of ventilatory support:

Suggested way to explain ventilatory support:

“When you are put on a ventilator, you are given drugs to make you drowsy and a tube is put down through your mouth into your windpipe. This tube is then hooked up to a machine that helps you breathe. You cannot talk while this tube is in your mouth but you can write or mouth

words to communicate with us. You cannot eat while this tube is in and we will need to put another smaller tube, either through your nose or mouth into your stomach to feed you. Both of these tubes are taped to your face to hold them in place. While we can give you some drugs like morphine and to make you more comfortable while you have the breathing tube in, it still will feel strange and will give you a sore throat.

We would also likely need to place a monitoring device, like an intravenous into an artery in your wrist or your leg so that we can follow your oxygen levels and your blood pressure.

While it is difficult to predict how long you will need life support, most people will need to be on the ventilator at least a week. But it could be shorter than this or a lot longer depending on why you need it.”⁴⁰¹

Where a specific wish about ventilation is being solicited, patients should be made aware, for example, that they will be unable to talk or eat when ventilated.

As noted elsewhere, Ontario has adopted a policy of contextualized decision-making. Ontario law balances respect for prior capable wishes expressed by the patient with limitations on the ability of patient’s to pre-consent to treatment. However, the increasing prevalence of advance care planning workbooks containing specific yet limited information threatens this balance by encouraging low-quality expressions of future care wishes – which may not advance patient autonomy. In our view, energies within the health sector should first focus on obtaining informed consent to a plan of treatment. Second, we believe it would be preferable to solicit values-based and less specific wishes to be interpreted by SDMs, rather than individual wishes about each treatment option.

In the fall of 2013, the Speak-Up Initiative released a line of Holiday Cards encouraging individuals to share their future care wishes. While this is certainly a

laudable goal, some of the information in these cards may be legally incomplete, such as the below statement:

You're critically ill or injured, and you can't communicate your wishes for care. And so someone – a loved one, a friend– has to make those decisions for you, during a time of great stress.

An advance care plan lets you share your wishes with others so that you'll get the care you want, and they'll have the confidence to make decisions for you. It's the perfect gift for your loved ones.⁴⁰² [Emphasis added]

The difficulty with the above quote is that the underlined passage could be interpreted as meaning that any “loved one” or “friend” may make health care decisions for an incapable adult – which is incorrect if decisions are to be made by a default SDM (who may or may not be a loved one or friend). While the document likely was meant to refer to a loved one or a friend appointed as an attorney pursuant to a power of attorney for personal care, this limitation is not explicitly stated.

3. *Cancer Care Ontario*

We located two documents from Cancer Care Ontario that are intended to provide guidance to health practitioners in operationalizing advance care planning: the “Advance Care Planning Quality Improvement Toolkit” (the “Toolkit”)⁴⁰³ and tool entitled “Advance Care Planning with Cancer Patients.”⁴⁰⁴

The Toolkit is intended as a guide for health practitioners to assist with implementing advance care planning discussions as part of a quality improvement program. This document is comprised of two parts: a system for initiating and then tracking improvements in advance care planning and

resources for guiding advance care planning discussions with patients. This document borrows heavily from the CHPCA “Speak-Up” initiative discussed above, refers health practitioners to the Ontario specific workbook, and also quotes extensively from the “Speak-Up” initiative glossary of advance care planning medical terms. As such, the Toolkit could benefit from the same suggestions that were discussed above.⁴⁰⁵ More fundamentally, this document, like almost every other document we reviewed, could be enhanced by situating advance care planning squarely within the law of health care consent – which is where the legislature chose to place it (while still recognizing the different legal effect of informed consent and expressions of wishes, values and beliefs).

On a more concrete level, the “Toolkit” refers health practitioners to other organization’s materials for additional information on advance care planning. However, it could be improved by distinguishing between Ontario specific materials and materials from other jurisdictions (particularly the United States) that have significantly different legislation.⁴⁰⁶ For example, it refers Ontario health practitioners to the sample American Family Physician Sample Advance Directive, which purports to be a combined Living Will and Durable Power of Attorney for Health Care – neither of which is a document created under Ontario law.⁴⁰⁷ The Toolkit also refer health practitioners to an American advance care planning program entitled “Respecting Choices” run by the Gunderson Health System in Wisconsin.⁴⁰⁸ Again, this program may not be in keeping with Ontario law.

With respect to this last critique, we should note that, under the item “Other Canadian resources”, the Toolkit states that “[o]ther jurisdictions have also developed templates and workbooks. Remember, these may not be congruent with the legal framework for advance care planning in Canada.”⁴⁰⁹ While helpful, this disclaimer could be improved by recognizing that there is no Canada wide legal framework for advance care planning. It would more accurate to say, ‘... for advance care planning in various Canadian jurisdictions’, since there is no uniform framework for advance care planning at a national level.

Another potential problem with the “Toolkit” is that it encourages health practitioners to set objectives that could be interpreted as requiring that all patients advance care plan. As an example, the “Toolkit” asks health practitioners to set advance care planning objectives, such as: “All patients over the age of 50 years have an advance care plan.”⁴¹⁰ While this objective seems innocuous by itself, in practice the authors have seen such objectives interpreted as a requirement that all patients engage in advance care planning, whether they wish to or not. In Ontario, patients cannot be forced to advance care plan.

With regard to Cancer Care Ontario’s “Advance Care Planning with Cancer Patients,” this document summarizes evidence based research on the benefits of advance care planning and best practices. This document primarily addresses clinical issues, and therefore should be viewed in that light. However, the authors’ concern with this document is that it relies heavily on, and refers clinicians to, studies relating to advance care planning in other jurisdictions that

may not be applicable in Ontario. While this document recognizes that the laws relating to advance care planning and advance directives vary across Canada and that health practitioners should be aware of the relevant legislation within their own jurisdiction, this document would do well to more closely within Ontario's law of health care consent.⁴¹¹

More broadly, neither document distinguishes between advance care planning through the expression of wishes, values and beliefs and informed consent to future treatment. Where a patient is informed of the risks and benefits of a treatment related to his/her present health condition, the patient is likely engaged in the process of giving informed consent to treatment. Unfortunately, these documents could be interpreted as stating that all discussions regarding future treatments are part of advance care planning. By referring to all future care discussions as advance care planning, this could detract from patient autonomy by removing the degree of certainty associated with health care consent. This confusion is further reinforced by the fact that "Advance Care Planning with Cancer Patients" refers to advance care planning as "decisions" – rather than wishes, values and beliefs.⁴¹²

4. Checklist for meeting Ethical & Legal Obligations (ChELO)

ChELO is a system for ensuring the health practitioners comply with their obligations in proposing a plan of treatment to a patient or, if incapable, a patient's SDM. Currently, ChELO is part of a pilot project at William Osler Health System ("WOHS") in Brampton, Ontario. In preparing this Paper, we reviewed

both an article explaining the purpose and internal logic of ChELO,⁴¹³ as well as screenshots of the ChELO application for use on mobile devices.⁴¹⁴ We also spoke with the WOHS ethicist.

ChELO is designed to assist health practitioners in preparing a plan of treatment, and ensuring that they are speaking with the correct SDM who has been appropriately advised of his/her obligations under the *HCCA*. As a checklist, this system has many impressive qualities that could significantly reduce basic errors made by health practitioners. However, like many of the other materials we have reviewed, ChELO could be read as instructing health practitioners to interpret a patient's wishes, values, and beliefs in preparing and proposing a treatment plan:

Form and Propose a Treatment Plan to the Patient or SDM

Treatment plans are defined in the *HCCA* as being proposed by one or more practitioners to resolve a condition or number of conditions. A plan of treatment may also include withholding or withdrawal of a treatment. Healthcare professionals meet their ethical and legal obligations when then propose a treatment plan that is medically indicated and that reflects a patient's previously expressed (when capable) wishes applicable to the circumstances and/or the patient's values and beliefs. There is no ethical or legal obligation to propose a treatment plan that is not medically indicated. However, it may be unclear whether a life-sustaining treatment is indicated or not.⁴¹⁵

The potential difficulty with the above passage is that it could be interpreted as usurping the role of the SDM as the interpreter of the applicability of prior capable wishes. ChELO appears to instruct physicians to pre-screen patient treatments based on their own interpretation of patient's wishes. In short, ChELO flips the legislative order: the SDM needs to first know treatment options before considering wishes, values, and beliefs. Practically, ChELO could result in

decision-making errors if SDMs are aware of more recent applicable prior capable wishes than those relied upon by health practitioners to pre-screen treatment options.

We have been advised that health practitioners would be expected to advise SDMs of alternative treatments that are not being proposed due to prior capable wishes expressed by the now incapable patient. This would be part of health practitioners' general obligations in obtaining informed consent to treatment from an SDM. This expectation, if followed in practice, goes a long way toward resolving the authors' concerns about possible misinterpretations of the ChELO program. Specifically, it would give an opportunity for SDMs to advise of more recent applicable prior capable wishes expressed by the patient. However, it would not resolve the fact that health practitioners are interpreting and applying, at first instance, prior capable wishes when this should be the role of the SDM. We recommend editing the checklist to clarify that the SDM is the interpreter of wishes, values and beliefs.

It is clear that ChELO has many helpful and impressive features. It could be improved by recognizing the role of the SDM as the interpreter, at first instance, of the prior capable wishes of the patient (except in an emergency). ChELO could also be improved by encouraging physicians to have more of an in-depth discussion with the SDM about the patient's current health condition at the time the patient's prior capable wishes are discussed. ChELO could also be improved by employing more of the language of the *HCCA*, rather than the

language of ‘living wills’ and ‘advance directives’, which may contribute to some of the misunderstandings observed in Ontario.⁴¹⁶

5. Fraser Health Medical Orders for Scope of Treatment (MOST)

In British Columbia, Fraser Health has developed a system of medical orders for scope of treatment. This system is primarily comprised of a standardized form to record physicians’ orders regarding end-of-life medical interventions, standardized forms recording patient advance care plans, and policy documents explaining how to use these forms. We have learned that all or part of the Fraser Health MOST program is being implemented in at least one hospital in the Greater Toronto Area, and are aware that the Fraser Health MOST documents are being widely circulated among health practitioners for consideration.

The Fraser Health MOST system cannot be implemented in Ontario without significant revisions, as it contains numerous statements that are incorrect in Ontario, both on the forms themselves and in the policy documents. Used without adaptation, the Fraser Health MOST form contains many of the common misconceptions with respect to Ontario law previously identified in this Paper, in that it:

- (a) does not distinguish between, and appears to confuse, consent to treatment, prior capable wishes, values and beliefs (advance care planning), and physician orders based on the standard of care;
- (b) could be interpreted as instructing SDMs to express wishes, values, and beliefs on behalf of patients; and,

(c) could be interpreted as instructing physicians to act directly on advance directives without first turning to the patient's substitute decision as interpreter.

More broadly, while helpful in British Columbia, the Fraser Health MOST program references a statutory scheme for substitute decision-making that is very different from the scheme set out in the *HCCA*. For example, the MOST Policy document⁴¹⁷ provides as follows:

3. The MOST is completed as an outcome of Advance Care Planning (ACP) conversations with an adult capable of providing consent to health care, or if the adult is not able to provide consent, his/her substitute decision maker(s) [(SDM(s))]. Other family members or friends may be consulted as appropriate. Conversations are documented on the ACP Record Form (Appendix 2).

...

20. ACP conversations are on-going and ideally take place early in a patient's course of care and/or treatment with the capable patient or, if not capable, with the Substitute Decision Maker (SDM). ACP conversations include:

- a. Understanding the adult & what is important to them. This should involve substitute decision makers.
- b. Provision and clarification of medical information about disease progression, prognosis, & treatment options to clarify goals of care and consent decisions.
- c. Interdisciplinary involvement and utilization of available resources/options for care.
- d. Documentation of ACP conversations and MOST, as well as care plans which include management of potential complications.

...

22. An Advance Directive that meets the legislative requirements set out in the Health Care (Consent) and Care Facility (Admission) Act must be followed. Exceptions are as noted in the Definitions section.⁴¹⁸

As the above passages do not expressly distinguish between consent and the expression of wishes, values, and beliefs, they could be interpreted as

encouraging physicians to have SDMs advance care plan on behalf of patients. The MOST Policy document does not recognize that SDMs cannot express new wishes on behalf of patients – they can only recount prior capable wishes expressed by the patient. This Policy document also could be interpreted as suggesting that physicians can directly implement advance directives, without utilizing the SDM as the interpreter of their applicability – through reference to advance directives being followed under the British Columbia *Health Care (Consent) and Care Facility (Admission) Act*.

Perhaps more importantly, the MOST Forms and Policies encourage ‘tick-box’ advance care planning, that will be implemented through physicians’ orders on a patient’s hospital chart. The risk in creating such systems is that health practitioners may bypass SDMs and informed consent generally, in favour of implementing orders previously placed on the patient’s hospital chart. The risks of such ‘tick-box’ advance care planning are borne out in the results of our focus groups with health practitioners, discussed below.

We should note that, in considering the Fraser Health MOST forms, the Ontario Ministry of Health and Long-Term Care also has a Do-Not-Resuscitate Confirmation Forms [“DNR Confirmation Form”].⁴¹⁹ The DNR Confirmation Form is designed for use by paramedics and firefighters (who are not covered by the provisions of the *HCCA* because they are not health practitioners) but who do provide resuscitation in emergencies. The form allows paramedics and firefighters to follow the directions of a health practitioner, and not initiate

resuscitation where a form has been completed with respect to a patient. While the DNR Confirmation Form plainly has a different purpose than the Fraser Health Most form, it does provide an example of a medical form that clearly distinguishes between a plan of treatment involving a DNR and the exercise of a health practitioner's discretion to refuse to offer resuscitation. Specifically, the DNR Confirmation Form provides that it can only be completed where:

(a) there is a plan of treatment in place for the patient that CPR not be provider; or,

(b) where a physician has determined that CPR will almost certainly not benefit the patient, that CPR is not part of the plan of treatment, and the physician has discussed this finding with the patient (or SDM if the patient is incapable).

6. Ontario Seniors' Secretariat Guide to Advance Care Planning

The Ontario Seniors' Secretariat has prepared *A Guide to Advance Care Planning* (the "*Guide*").⁴²⁰ ACE was directly involved and contributed to the drafting of this document when it was originally produced in 2001, but did not have final editorial control. The *Guide* is intended as a plain language document explaining the law of Ontario surrounding health care consent and advance care planning.

The *Guide* generally functions well as a plain language explanation of the law of health care consent and advance care planning in Ontario. However, some of the language chosen is less than ideal. For example, the *Guide* sometimes refers to patients as making "choices" when advance care planning (rather than expressing wishes) and states that an SDM will follow expressed

care wishes unless it is “impossible” to do so (without referring to the SDM’s determination of the applicability of such wishes).⁴²¹ These issues are common with many of the other documents reviewed in preparing this report. These language choices could cause patients to misunderstand some aspects of Ontario’s legal regime.

The *Guide* could be improved by more closely tracking the language in the *HCCA*. Even if the *Guide* were entitled ‘A *Guide to Health Care Consent and Advance Care Planning*,’ that alone might assist the public (as well as health practitioners) in understanding the connection (and difference) between consent and advance care planning.

As an aside, this document was created less than five years from the proclamation of our current legislation. At that time, the importance of using the language in the legislation in explaining health care consent and advance care planning (and the degree to which language choices and forms would drive practice) was not fully appreciated. For example, ‘wishes’ are different than “choices.” The use of the word “choices” to refer to advance care planning may have contributed to some of the observed confusion in Ontario surrounding the relationship between health care consent and advance care planning, particularly around who interprets a patient’s wishes, values and beliefs.

7. Interventions to Reduce Acute Care Transfers (INTERACT)

The Interventions to Reduce Acute Care Transfers Program (or INTERACT) is a system of quality improvement tools designed to reduce

transfers to hospitals from nursing homes, developed primarily in Florida.

INTERACT is comprised of:

- 1) Communication tools;
- 2) Care Paths or Clinical tools; and
- 3) Advance Care Planning tools.⁴²²

The authors have learned that INTERACT tools are being utilized by a number of long-term care homes in southern Ontario.

There are many excellent features of INTERACT, and the goal of reducing unnecessary acute care transfers is certainly a laudable one. In preparing this report, we only reviewed the Advance Care Planning tools available on the INTERACT website which, admittedly, appear to be a small part of this broader program. As with other advance care planning programs that have not been specifically adapted for Ontario, INTERACT forms and tools could inadvertently misdirect health practitioners in making or implementing advance care plans. For example, the template Advance Care Planning Tracking Form specifically suggests that an SDM (or “surrogate”) can advance care plan (without drawing a distinction between wishes expressed by the patient, ineligible new wishes expressed by the SDM, and consent) and does not contain a place to record if the patient is capable or incapable with respect to treatment. An excerpt from the template follows:

Advance Care Plan Review and/or Discussion⁴²³

Purpose of Review:

- Care Planning (*routine update*)
- Change in Condition
- Other(*specify*) _____

If discussion was held, with whom (*check all that apply*):

Resident
 Resident's surrogate; Name: _____
 No discussion held

Was a change in advance care plan or advance directive made? No Yes
(describe) _____

Staff or healthcare provider leading discussion:

Name _____ Title _____

Signature _____ Date of discussion ____ / ____ / ____⁴²⁴

This form could be improved by clarifying between the expression of wishes by the patient, and consent by the patient or SDM to treatment.

Similarly, the Advance Care Planning Communication Guide refers to legal documents that do not exist under Ontario law, stating that the guide will be helpful in discussions on: "Advance Directives – such as a Durable Power of Attorney for Health Care document, Living Will, and POLST and other similar directives."⁴²⁵ This could result in health practitioners mistakenly believing that written advance directive documents take priority of other prior capable wishes expressed by the patient.

Ontario health care institutions should not be directly implementing INTERACT forms and tools without adjustment for differences in Ontario law.

8. *Let Me Decide*

Approximately 25 years ago, Dr. William Molloy (and others) developed the "Let Me Decide" advance health and personal directive program.⁴²⁶ This program gained some traction in Ontario as a tool to record and interpret advance care plans and continues to be referenced by health practitioners to this

day.⁴²⁷ The “Let Me Decide” program involves the use of a “directive” form which asks numerous questions of patients regarding the care they wish to receive, and also employs a chart to be completed by patients expressing general wishes about what medical conditions are acceptable and intolerable.

The authors’ primary concern with the “Let Me Decide” program is how it could be used in practice (e.g., where it is used as a physician’s order by staff because the physician has signed the form). However, these forms are not physicians’ orders for treatment and are not detailed enough to amount to consent to a plan of treatment by the patient or SDM. Yet, staff at some health care organizations have inferred that they should take direction from this form and need not obtain consent from the patient or, if incapable, the SDM.

Another potential problem with the “Let Me Decide” form is that patients may unintentionally create a power of attorney for personal care by executing this form. The form is apparently intended to be executed by a patient when capable and signed by two witnesses. As such, this form might meet the legal test to be a power of attorney for personal care as defined under the *SDA*. However the patient signing the “Let Me Decide” form may not understand that it is a power of attorney for personal care because it is called a “directive.” The person signing may not understand that a power of attorney for personal care not only gives authority to the named substitute (the attorney) to make health care decisions for the grantor, but it also has the potential to give authority to the attorney to make decisions for the grantor about shelter, nutrition, safety issues, clothing, and

hygiene. That is much broader than health care. The validity of this power of attorney for personal care may then come into question.

Furthermore, the introduction to the directive explains to patients that they are stating their wishes “...should the time ever come when I am not able to communicate because of illness or injury” [Emphasis added].⁴²⁸ This is legally incorrect. The legal issue is not whether the person can communicate, but whether the person is mentally capable in respect to the treatment that is being offered. In some instances, patients are not readily able to communicate, but remain mentally capable. Efforts must be made to try to communicate with the individual, even if they have a communication disability. This may sound nit-picky, but it could be significant for the sub-set of capable patients who have a communication disability.

The next sentence in the directive provides that “This Directive should never be used if I am able to decide for myself. It must never be substituted for my judgment if I can make these decisions”.⁴²⁹ This is technically correct. However, it may be misleading because it makes it appear that directives speak to all parties where the patient is incapable. Under Ontario law, the directive only speaks to the SDM (except in an emergency), and the health practitioner must get consent or refusal of consent to the treatment even if the person expressed wishes in the directive. It is the SDM that interprets the directive not the health practitioner, except in an emergency.

In the authors' opinion, the Let Me Decide program should be significantly revised to comply with Ontario law.

C. Survey of Institutional Policies and Practices

1. Background

As part of this research project, ACE and DDO distributed a request to long-term care homes and hospitals seeking to obtain and review:

- (a) excerpts from training materials, guides, and/or operational manuals that relate to consent to treatment, advance care planning, and/or substitute decision making;
- (b) documents made available to patients and/or substitute decision makers relating to consent to treatment, advance care planning, and/or substitute decision-making (i.e. information pamphlets given to SDMs); and,
- (c) standardized forms, templates, tools, and questionnaires used by health professionals to record consent or advance care plans (i.e. level of care, DNR, and consent forms).

This request was primarily distributed through institutional organizations such as the Ontario Hospital Association, the Ontario Long-Term Care Association, and the Ontario Association of Non-Profit Homes & Services for Seniors. We would like to thank these organizations for their assistance and support of this project.

The authors received thirteen sets of documents from long-term care homes and hospitals. While we would have preferred to have more sources, the documents we received were from organizations covering a good geographic range of Ontario: including northern Ontario, eastern Ontario, southwestern Ontario, and the Greater Toronto Area. We received policies from teaching

hospitals, community hospitals, and mental health hospitals. We also received policies from municipal long-term care homes, non-profit long-term care homes, and private long-term care homes. Several of the policies were provided by large organizations that own/manage numerous long-term care homes throughout the province.

We should note that that these documents were provided voluntarily. In order to encourage participation in this research project, the authors undertook that any documents provided for this research project would:

- (a) be used solely for the purposes of research and law reform activities; and,
- (b) not be provided to third parties except with the written consent of the provider, with the removal of any information identifying the provider, or as required by law.

We also promised that this Paper would not identify specific institutions or persons in its discussion of the institutional survey. We would like to thank those organizations that participated in our institutional survey.

We have not commented on every form or all details in the forms which may merit attention, but have endeavoured to identify common themes or trends in the documents.

2. Forms Suggesting SDMs Can Advance Care Plan

Of the thirteen sets of documents reviewed, seven had forms and policies that either expressly stated that an SDM could express wishes, values, and

beliefs on behalf of incapable patients, or could be interpreted as allowing SDMs to fill this role. Almost all of the policies did not draw distinctions between:

- (a) consent to treatment by the patient or SDM;
- (b) expressions of wishes, values and beliefs by the patient; and,
- (c) SDMs recounting prior wishes of patients.

Two institutions' policies correctly noted that SDMs cannot advance care plan on behalf of patients.

This issue presented itself in the documents in a range of different ways. Several advance care planning forms reviewed were capable of being used incorrectly by health practitioners because they contained a signature line indicating that the form could be executed by an SDM. An example of such a form from a long-term care home is set out below:

ADVANCE DIRECTIVES

Level One – Supportive/Comfort Care

This includes, but is not limited to, the provision of measures available within the resources of the facility such as:

- Relief of pain;
- Oral fluids;
- Positioning;
- Mouth care;
- Treatment of fever;
- Oxygen administration (if available);
- Suctioning.

Diagnostic interventions and transfer to hospital will not normally be utilized for residents who request this level of Advance Directives. No cardiopulmonary resuscitation is requested.

Level Two – Limited Therapeutic Care

Care measures will include all procedures utilized in Supportive/Comfort Care as well as the administration of antibiotics if indicated. Transfer to hospital may be arranged to provide comfort/treatment measures beyond

One policy on “Communication of Prior Expressed Wishes” provided that, where there was no formal advance care plan on admission, issues surrounding end-of-life care and resuscitation should be discussed with the SDM, who can sign a directive. This policy also states that staff should impress upon the SDM that any directions provided are to be “based on what the resident would have directed...” This suggests that SDMs will be expressing new wishes on behalf of the patient, rather than simply recounting prior expressed wishes. Again, as this policy does not reference informed consent to treatment, this suggests that SDMs are advance care planning on behalf of incapable patients when signing advance directives.

3. Requirement for Signature of Advance Care Planning Forms by Health Practitioners

The form above requires signature by the patient’s health practitioner. The purpose of such a signature was not explained in any of the policies that accompanied the form. There is no requirement in the HCCA that the health professional sign the form. There is nothing technically wrong in having the health practitioner sign such a form however the risk is that the presence of such a signature infers that the document is a consent or a ‘doctor’s order’ and as such must be followed directly by staff without getting an informed consent from the patient if capable or the SDM when treatment is required. In the course of the authors’ legal practices, we have heard that staff interpret such documents in this manner.

4. Lack of a Consistent Framework for relating Health Care Consent and Advance Care Planning

The fact that many of the forms and policies reviewed could be interpreted as allowing SDMs to advance care plan is likely the result of a broader issue: the lack of a clear and consistent framework in institutional policies and forms for understanding the relationship between health care consent and advance care planning. A number of the forms that are labelled as Advance Directives are in fact documents that could be used to record an informed consent to a plan of treatment assuming the appropriate discussion and information has taken place with the SDM. Those documents, as consents, would then reflect the appropriate legal process.

However, even through this lens, the policies and forms reviewed reveal several divergent (and sometimes internally inconsistent) conceptualizations of the legal relationship between health care consent and advance care planning.

To give examples:

- a level of care form entitled “Advance Health Care Directive”, (similar in content to the form quoted above), contains the preamble:

Policy: Residents have the right to specify their health care wishes prior to an illness or injury that makes the communication of their wishes impossible. These wishes will never be used if the resident is competent to make these decisions. If the resident is already incapacitated, the Substitute Decision Maker will make decisions on the resident’s behalf. These decisions should be based on what the Substitute Decision Maker believes the resident would have chosen if they were capable.

This document is deemed legal and standing once signed by all parties and can be changed with the expressed

written consent of the resident, substitute decision-makers or Consent and Capacity Board Adjudication. [Emphasis added]

Reading this preamble critically, the form appears to have elements of both an expression of future wishes and a consent to treatment. Adding to the confusion, this document specifically provides that a substitute decision-maker may make decisions about how “life-threatening illness, illness or injury” should be managed. This form does not contain any language to suggest that health practitioners will disclose the risks and benefits of any treatment decisions discussed. As such, it is doubtful this form would qualify as an informed consent to treatment.

- an Advance Health Care Directives policy provides that:

An advanced health care directive is not consent to treatment. Members of the health care team providing care other than personal care are required to obtain consent for that treatment.

However, the same page of this policy also provides that:

Resident’s [*sic*] presenting with an advanced health care directive or living will, will have the wishes expressed in that document carried out by home staff as long as the wishes expressed do not require home staff to practice in conflict with professional standards...

These two paragraphs could be interpreted as having directly opposed meanings, and there is no explanation for how they should

be reconciled by a health practitioner. One statement provides that an advance health care directive is not consent, and the other provides that an advance health care directive will be carried out by staff, thus inferring that it is a consent. This policy does not limit the application of advance health care directives to emergencies. As such, it would seem that this document is internally inconsistent.

Also, the statement that a resident’s wishes expressed in a living will will be carried out by staff is either legally incorrect or incomplete as an expression of Ontario law (as the applicability of wishes should be interpreted by the SDM,

and only applied after informed consent is obtained – except in an emergency). This type of statement also appeared in a number of other policies of other health facilities.

- One health facility has two forms, one entitled “Record of Consent to Advance Care Planning” which has two parts, one part to be executed by the Capable patient or the SDM of the incapable patient and the second part which is only to be signed by the patient if capable. The second form called “Expressed Wishes Form” is for signature by an SDM of an incapable patient.

Overall these two forms accurately reflect the differences between Informed consent and Advance care planning, and accurately capture who can execute each type of form (the patient or the SDM) . However, the first form has an incorrect title and could cause confusion for health practitioners as the first part of that form is clearly the written consent to a plan of care and records the result of an informed consent process and is not an advance care plan.

The second part of the form is tick-box short version of a level-of-care form concerning comfort measures at end of life and wishes about transfer (or not) to hospital. It is clearly and correctly marked as only being able to be completed by a capable resident, as it is a type of advance care plan. This form does not include any statement that it is the SDM that is required to interpret and apply such wishes and not the health practitioners subject to the emergency exception. Looking at the form it is not possible to know whether in practice the health practitioners would know to turn to the SDM or whether they use this form as a consent although it is only a generalized advance care plan.

- This same organization also has an “Expressed Wishes Form” which can only be completed by an SDM, which contains this caveat:

This form can only be completed by the substitute decision maker if the resident is incapable and wishes were expressed by the resident when capable.

The drafters of this form apparently (and correctly) distinguished between the expression of new wishes by the SDM and the

recounting of prior capable wishes expressed by the patient. This is a more nuanced understanding of advance care planning than is demonstrated in other advance care planning forms and policies.

What these examples of policies and forms show is that health care organizations appear to have different understandings of how the requirement to obtain informed consent to treatment relates to advance care planning, advance directives and other level of care forms. In many of the advance care planning forms that we reviewed, it is very difficult to determine if the form was meant to record patient wishes, new wishes created by the SDM, informed consent to treatment, or some combination of the above. Some of the forms appear to contemplate a third option: a physician do-not-resuscitate order completed in the absence of patient consent or an advance directive.

While imperfect and generic forms would not be a concern if health practitioners consistently and correctly understood and applied the law, as we set out below in our discussion of our health practitioner focus groups, the use of these forms appears to cause confusion.

5. Use of Extra-Provincial Materials

As we suspected from our review of the regulatory policies and forms made available to health practitioners publically, extra-jurisdictional materials are being used in Ontario without appropriate adaptation. One of the long-term care homes participating in our survey appears to be using a system of forms developed in Alberta, without adaptation to Ontario law. This is one of the sets of

forms, discussed above, that could be interpreted as allowing SDMs to advance care plan on behalf of incapable patients. Similarly, one of the policies reviewed referred health practitioners to extra-provincial resources and U.S. materials if they have additional questions – including the Fraser Health forms discussed above, advance care planning kits of the California Medical Association, and advance directive forms from Manitoba.

This again suggests that health organizations are not aware of important differences in Ontario law which may make extra-provincial forms inapplicable.

6. Tick-Box Forms

Almost all of the forms we reviewed were tick-box forms: forms which require patients to choose from a narrow field of pre-selected options for future care. An example of such a form can be found in the level of care advance directive form quoted above. While more will be said on these forms later, it is important to note that the use of tick-box advance care planning forms appears to be widespread in Ontario. Our concern with these forms is that they unduly restrict the wishes that may be solicited from patients, and the information expressed therein may not be particularly useful to a future SDM (if indeed one is consulted). These forms also generally make no attempt to contextualize the patient's expression of wishes in their current health condition, or to discuss the risks and benefits of treatment. Instead, they simply request that patients express future wishes about, for example, whether they want to be hospitalized and receive antibiotics, without grounding the application of that wish in likely

hospitalizations relating to the patient's present health condition. From the authors' observations, these level-of-care forms in particular seem to be used frequently as consents although portrayed as advance directives and although completed without the information required for a valid informed consent.

7. Other Legal Issues Identified

We noted numerous other legal issues in the forms and policies reviewed. Many of these issues were minor, and need not be raised in this Paper. Several were interesting, and accord with ACE and DDO's broader experience.

The standard consent to treatment form of an eastern Ontario community hospital provided that, in consenting to surgery:

If my physician discovers a different, unsuspected condition at the time of my surgery, I authorize him/her to perform such treatment as he/she deems necessary. That treatment may include a blood transfusion before, during or after surgery to compensate for loss of blood or severe anemia. Blood transfusion involves additional risks including infection, allergic reaction or incompatible transfusion reaction.

No attempt is made in the consent form to limit the scope of this additional consent to emergencies, nor to foreseeable issues that arise in surgery that are related the patient's present health condition. There appears to be no disclosure of the additional risks and benefits of treatment related to these unexpected conditions (beyond blood transfusions). As such, this clause is simply ineffective to cover informed consent to treatment. In the authors' experience, clauses such as the above in consent forms are fairly common. The authors' frequently come across long-term care home documents that provide that a resident must consent

to any treatment proposed by a health practitioner at the long-term care home.

For example, one document provides as follows:

I hereby consent to medical treatment and appropriate nursing care which the attending physician and the facility staff may consider necessary and advisable.

Consents to treatment given pursuant to such blanket agreements are plainly unlawful and ineffective.

One southwestern Ontario community hospital was still using substitute decision-making forms from the repealed *Consent to Treatment Act* (the predecessor to the *HCCA*). Section 17 of that *Act* required that SDMs certify, *inter alia*, that the incapable person would not object to the SDM acting. SDMs in Ontario have not been legally required to provide this certification for almost 20 years. In a similar vein, a chain of long-term care homes appears to require that SDMs sign a form stating that they have been in contact with the patient in the last 12 months. This is also not required in Ontario for an SDM to be legally authorized to act. Both of these policies could unlawfully restrict the ability of a patient to have access to their statutory default SDM.

One health care organization is using a hierarchy list of SDMs that is incorrect. It lists the incapable person's child in priority to the incapable person's parent instead of ranking them equally on the same level. Of greater concern is that it includes the old definition of spouse in the policy document which recognizes only spouses that are of the opposite sex and does not recognize same sex spouses as provided by law in Ontario for several years now.

The Management of Life Threatening Illness Policy of one mental health facility states that:

If the patient is capable, he/she is to complete a POAPC (as per the SDA) naming an attorney for personal care and setting out instructions for management of life- threatening illness, including implementation of the patients wish for resuscitation to be attempted or DNAR.

It would appear by this statement that this facility requires all patients to complete a power of attorney for personal care (POAPC). That is not a requirement in any Ontario legislation that applies to any health facility and the authors would submit that such a requirement is not lawful. It is not clear from this policy whether SDMs on the HCCA hierarchy who are not attorneys named in a patient's POAPC would be recognized as SDMs for patients receiving care at that facility. As well a health facility policy cannot require a patient to give instructions or express wishes about management of a life threatening illness or a plan for resuscitation either to be applied by the SDM in the future or to be acted upon by staff in an emergency.

The policy could be amended to require staff to discuss with patients who would be their future SDM, should they become incapable of treatment decision-making, using the SDM hierarchy list in the HCCA to identify the default SDM and advising the patient of the option of preparing a POAPC if they do not want the default SDM to act for them in the future. As well, the policy could be amended to reflect that discussions about end of life decision making be undertaken with patients where appropriate. However the policy cannot require

patients to do what is described in this paragraph as a condition of getting care at that facility.

A southwestern Ontario hospital states in its Consent Protocol that, where no translator is available to assist with communication with a patient, that patient can be deemed incapable. This is incorrect. Under the *HCCA*, patients can never be deemed incapable simply because they cannot communicate. In fact, the presumption of capacity would continue to apply, unless there was some other reason to doubt the patient's capacity. Instead, the *HCCA* contains provisions addressing this exact situation: treatment can be provided in an emergency, but only for a reasonable time to locate an interpreter. The patient remains capable at all times.

Several of the policies reviewed confused the decision-making obligations placed on SDMs. This presented itself in different ways, such as in policies:

- stating that SDMs act in the patient's best interests without first recognizing that applicable wishes take priority in SDM decision-making before the best interest test is applied; or,
- stating that, where there are no applicable wishes, the patient is required to act in the patient's best interest, but neglecting to include in the matters to be considered by the SDM the wishes, values and beliefs of the patient.

Another form that appears to be a consent form to be signed by SDMs when they provide substitute consent for an incapable patient includes the statement:

Another family member may be entitled to make treatment decisions and may choose to accept this responsibility. Please indicate a family member who may be willing to accept this responsibility

It is not clear what is intended by this inquiry on the form. It could be interpreted as permitting the highest-ranking SDM as being able to delegate the decision making authority to another family member of the SDM, which by law is not possible. However, it is a scenario commonly encountered by the authors in their practices. If the highest ranking SDM is not willing to act, then the health practitioner must turn to the next highest-ranking SDM and determine whether that person meets the requirements to act as SDM.

Lastly, one form appears to draw a distinction between incapable patients' "SDM/POA" and the patient's family, while apparently allowing either to fill out the form. In the experience of ACE and DDO, this is a common error on long-term care forms, with documents distinguishing between attorneys for personal care and family members, despite the fact that they may both be SDMs under the *HCCA*. Similarly, ACE and DDO routinely encounter health practitioners who believe attorneys for personal care are the only true SDMs, and that a power of attorney is necessary to act. ACE and DDO also routinely encounter health practitioners who refer to a patient's 'next of kin', as if this were a legal category of SDM. To be fair, this is also captured in the electronic fields created in electronic medical records, where a "NOK" field must be filled out with no distinction as to whether that individual would necessarily be an SDM, or even whether the patient in such a case is even incapable for specific treatments.

D. Focus Groups

1. Health Practitioners

(a) Background

Consultations and meetings with health practitioners for this project took place primarily between October 2013 and late November 2013. The breakdown of health practitioners at each meeting varied. At some meetings, the participants were primarily physicians. At other meetings, the participants were a broader cross-section of health professionals. As examples, our meetings with Community Care Access Centre staff were primarily comprised of nurses and social workers. Our meetings with long-term care home staff were comprised of both regulated (i.e. health practitioners) and unregulated health professionals.

Some of our consultations for this report were incorporated into scheduled educational sessions for health practitioners given by the authors. These educational sessions took place in Sarnia, Chatham, Windsor, Sudbury, and Toronto. Other consultations occurred during separately scheduled meetings specifically for this research project in Sarnia, Chatham, and Windsor (organized with the assistance of project staff at the Erie St Clair Local Health Integration Network (LHIN)) and in North Bay (organized with the help of a palliative care project manager at the Northwest LHIN).

Neither the sampling of health practitioners, nor the phrasing of questions and follow-up questions to participants, were intended to reach to the level of a

formalized scientific study. Instead, these were viewed as more informal stakeholder consultations.

A variety of common issues and themes in relation to this report were identified through the course of these meetings, which are set out below.

(b) Lack of understanding of the connection between Health Care Consent and Advance Care Planning

Several health practitioners made comments suggesting that they had not thought that consent and ACP were conceptually or legally related. They expressed their understanding that advance care planning was a discreet process, separate and distinct from the process for obtaining informed consent to treatment or a plan of treatment. Health practitioners commented that this understanding was founded upon various public advance care planning awareness campaigns that do not refer to informed consent, but focus only on soliciting and recording advance directives and advance care plans.

Where these comments were raised, the authors followed-up and inquired how the participants understood advance care plans being solicited from patients would be used. A common response was that the participants believed that any written advance directive or “living will” would provide health practitioners with information on how to care for a patient in the future. However, these health practitioners did not mention, or did not appear to understand, even when asked, that in using advance care planning documents consent to treatment was still required. They also did not understand that some of the discussions that they had had with patients were not advance care planning but were what was

required to get an informed consent (in fact, in some examples they had unknowingly obtained an informed consent to treatment and not merely an advance care plan).

Some health practitioners suggested that a written advance directive would trump an informed consent from either the capable patient or the SDM for the incapable patient. Similarly, some participants were not aware that the terms “advance directives” and “living will” were not used in Ontario law, and were not aware that wishes could be expressed orally, in writing, or communicated by alternative means with equal effect. Many health practitioners did not seem to understand that wishes, however expressed, needed to be interpreted and applied by the SDMs (except in an emergency) and not by themselves in making treatment decisions.

(c) Identifying the correct SDM

At almost every consultation session, there were numerous health practitioners present that appeared to not understand the hierarchy of SDMs in the *HCCA*, and how to identify the correct SDM for an incapable patient. The misunderstandings were of various types including:

- *The belief that the only SDM is an attorney appointed pursuant to a power of attorney for personal care.*

Several health practitioners stated that they needed to find the appropriate “POA” when presented with an incapable patient. Some physicians stated that their practice was to ask for the patient’s “POA,” but not to ask patients for names of other possible SDMs.

One physician stated that he understood that every person should prepare a power of attorney for personal care because, otherwise, an incapable patient would not have an SDM for health care. When it was explained to this physician that a power of attorney for personal care is only one type of SDM, and that there is a hierarchy list, this same physician commented that the health record forms in the facility at which he worked only listed “POA” – and that this was the cause of his confusion.

In discussing what was needed to “prove” that someone was the proper SDM, one nurse said she would ask family members for the “papers.” When asked “what papers”, this nurse responded that she required a “POA” - even though this discussion occurred in relation to a hypothetical scenario in which an incapable patient had not previously prepared a power of attorney for personal care and the hierarchy of SDMs had just been reviewed in the education session.

A number of health practitioners continued to refer to the SDM as the “POA” even though, in the example, it was clear that the SDM was the adult child – as opposed to an attorney for person care.

- *Belief that health practitioners must take direction from an attorney named in a power of attorney for personal care even if it was questionable whether this document was valid*

In one session, an example was given of the appearance of a new power of attorney for personal care that, in the example, allegedly had been executed by the patient although the patient had been incapable of treatment decision-making for some period of time and it was highly unlikely that the patient had become “capable” even for a short time to execute a new power of attorney for personal care. In the discussion that followed, it appeared that some health practitioners believed that they would be obliged to take direction from the attorney named in the new purported power of attorney for personal care simply because it was an executed document.

- *Misunderstanding the HCCA hierarchy*

Although it was clear that many health practitioners knew there was a hierarchy list of SDMs, the exact hierarchy (who is on the hierarchy) was not fully understood. Few health practitioners understood that the third ranking SDM is the patient's "representative" appointed by the CCB, and that lower ranking family SDMs (and friends of the patient) could apply to the CCB to trump higher ranking SDMs (except the attorney for personal care or the Guardian of the Person). When the representative's role was described, one health practitioner disagreed with the fact that a friend of a patient could apply to be a representative over the patient's spouse or children, and expressed doubt that even if the person was appointed as representative that his/her authority would be recognized.

Despite the hierarchy, some health practitioners appeared to believe that any individual who claimed that they were a relative of the incapable patient could act as their SDM. These health practitioners were not aware of the caveats required by s. 20(4) of the *HCCA*.

Several health practitioners did not know that the Public Guardian and Trustee would be the SDM of last resort. Even if they did know that the Public Guardian and Trustee is the SDM of last resort, some did not know how to contact the Public Guardian and Trustee to play this role. Some health practitioners stated that they had called the Public Guardian and Trustee on some occasion but that that office had refused to act. When probed for more information on the circumstances of this call, it would appear that one of these health practitioners had telephoned the property management unit at the Public Guardian and Trustee, and not the treatment decisions unit. Two health practitioners stated that the Public Guardian and Trustee office had told them to use a friend of the patient as the SDM if there was no family.

One physician stated that it was his practice to act as his incapable patient's SDM if the patient had no family. This physician appeared to be completely unaware of role of the Public Guardian and Trustee.

- *How long and how well to search for SDMs*

A number of health practitioners asked questions about how long they should look for SDMs before moving on to another SDM or the Public Guardian and Trustee. Most health practitioners who asked these questions did not appear to know that one of the criteria that needed to be applied to the person to act as SDM was that the SDM would need to be “available.” Some health practitioners commented that SDM absences caused problems for patients if the SDM could not be contacted in a timely manner. When asked if the health practitioners told SDMs that they would need to be “available” and whether they had recorded various contact numbers for the SDMs, most replied that they did not advise SDMs of this requirement and were not aware if the facility at which they provided care gave such information to SDMs.

There was also not a clear understanding among participants on what ‘availability’ meant with regard to SDMs— several asked questions about how long a time is appropriate to wait for an SDM to return a telephone call. All health practitioners who asked this question did say that they would consider a patient’s needs and possibly treat on an emergency basis if the SDM could not be reached. However, these questioners appeared not to be aware of the health practitioners’ legal ability to move to the next highest ranking SDM where a higher ranking SDM is not available.

Some health practitioners thought that they (or someone on their team) was expected to do extensive searches for possible SDMs for the patient even though the patient may have had little or no contact for a considerable period of time with a particular potential SDM, and no specific contact information was readily available. To repeat an example given by a health practitioner, if told that the patient “may” have a daughter living in another city, this health practitioner understood that someone on the team would be expected to hunt down that daughter no matter how long that took.

- *Scope of authority of SDMs*

Several health practitioners at a number of the meetings appeared to believe that an attorney appointed in a power of attorney for personal care automatically had more authority or power than other default SDMs on the hierarchy. In effect,

it would appear that they understood that an attorney under a power of attorney for personal care was as a ‘Super SDM’ and in some way was different than other SDMs. Some health practitioners thought that if an attorney was appointed under a power of attorney for personal care, they could get direction from that attorney even if the patient was capable. Also some health practitioners thought that an attorney for personal care could choose an alternative SDM to act for the patient (for example, if the attorney was away on vacation or didn’t want to continue to act as SDM). These health practitioners appeared not to understand that the attorney did not have authority to assign or transfer decision-making authority, or that the health practitioner should be turning to the next highest ranking SDM if the attorney was no longer “willing” or “available” to act.

One emergency room physician did state that he would take direction from an SDM to do a particular treatment for a patient even if he knew that that patient would not have wanted the particular treatment and in fact had given an informed refusal of the treatment. The physician said he felt that he had to provide the treatment requested by the SDM or risk “being sued”. When asked whether he was aware of possible applications to the CCB to have a hearing as to whether the SDM was acting in accordance with S.21 of the *HCCA*, or whether he was aware of the duty of health practitioners to explain to SDMs the requirement to make decisions in accordance with patient’s expressed capable wishes or the patients best interests if wishes applicable to the treatment options was not known, he and other participants replied that health practitioners were not necessarily aware of the CCB application option. This physician further stated that, even if they were aware of this option, few would want to go to the CCB. Several health practitioners stated they weren’t “supported” in making such applications in the health environments in which they worked, that the application would take too much time, and that it simply was easier to do what the SDM wanted.

- *Basics of the HCCA Hierarchy*

Several health practitioners appeared not to understand the fundamentals of the hierarchy of SDMs, such as that:

- the Person highest ranking that meets the criteria to be an SDM would be the SDM for the patient;
- if there were multiple equally ranking SDMs that all were entitled to act or that they could choose amongst themselves SDMs who would act; and,
- if equally ranked SDMs could not agree, they could turn to the Public Guardian and Trustee for a Decision.

Some health practitioners thought that they could require that one SDM of the equally ranked SDMs act as spokesperson and only contact for health practitioners. Other health practitioners were not certain how to manage the multiple conflicting SDM, and thought that whatever decision was most recently made by any one of the multiples would be the legally effective decision - even if different SDMs gave conflicting decisions immediately prior.

- *Qualifications to be SDM*

A number of health practitioners were not aware of the requirements to be an SDM set out in the *HCCA*. They did not know that if the highest ranking person in the hierarchy did not meet these requirements that they could move on to the next highest ranking person.

At almost all meetings, a question was asked about SDMs that the health practitioners believed were “incapable” to make treatment decisions for the incapable patient. In these discussions, it appeared that some health practitioners were not aware that they have the ability and responsibility to determine whether the highest ranking person in the hierarchy is capable or not for treatment decision-making.

Interestingly, some health practitioners stated that an SDM is incapable when that SDM is, in the opinion of the health practitioner, acting contrary to the best interests of the patient. This conflates the test for capacity with the test for best interests.

(d) Forms and Medical Records

Based on comments from health practitioner participants, it would appear that health care organizations' forms drive practice. Forms that refer to "advance directives" or use other language that is not in the *HCCA* reinforce health practitioners' understanding or misunderstanding regarding health care consent and advance care planning. For example, forms may refer only to a patient's "next of kin" and not list who would be the patient's SDM if the patient should become incapable. Similarly, forms may list only a "POA," with the result that health practitioners think that only attorneys for personal care are SDMs, or in some cases, that the patient is incapable and an attorney for personal care has authority to act, even in instances when the patient remains capable.

In particular, at our consultations with health practitioners, we discussed forms related to advance care planning and to specific end of life care (e.g. No CPR/DNR). Health practitioners generally did not understand the limitations of these forms, and many participants seemed to believe that level of care forms were the equivalent to an informed consent, even though they are often executed by patients or SDMs without information about the patient's present health condition or treatment options. Some health practitioners did comment that they did not like the forms in their institution, but thought that these forms were required by Ontario's Ministry of Health and Long-Term Care (although these forms are not required by the *Long Term Care Homes Act*).

Some health practitioners remarked that they wanted documentation on the patient's chart so that they would "know what to do at 2:00 am" if the patient had some type of acute episode. When asked whether treatment could be provided in such an episode on an emergency basis, health practitioners did not feel comfortable providing treatment in an emergency and preferred to have some directions on the chart, even though vague, general and uninformed. Health practitioners also expressed concern about the amount of time it would take to have in-depth discussions with the patient to obtain consent to a plan of treatment to address the same treatment options. Tick-box forms addressing acute treatment were perceived as more convenient and easy, even if not specific.

There were some discussions about what selections on tick-box level-of-care forms actually meant. When a long-term care resident has ticked off the statement that he or she would not want to be transferred to a hospital, a number of health practitioners advised that they took that statement literally - that there would be no reason to transfer a resident to a hospital for treatment. However, some health practitioners also stated that transfer to a hospital would be appropriate in certain circumstances, even where a resident had ticked-the-box advising he did not want to be transferred to a hospital, because some treatments could not be delivered appropriately in a long-term care home. One example discussed involved a palliative care patient who needed to go to hospital for a short-term comfort treatment, but then was transferred back to the

long-term care home for continued care. Some physicians thought that this patient would not be able to be transferred to a hospital for comfort care if the tick box form had been completed as described, whereas others physicians did think that the transfer could occur because the patient would not be remaining at the hospital long term.

This type of confusion around the meaning of level-of-care forms has also been identified in matters on which ACE has been consulted by families of long-term care residents, and that DDO has been consulted on behalf of long-term care homes. One such example was where a physician thought that “only comfort care” meant that he would have to take the patient off all medication, even medication used to treat the patient’s Parkinson symptoms.

At many education events conducted by ACE staff for physicians (beyond those conducted for this research project), ACE lawyers have been asked why long-term care homes may transfer residents to a hospital for treatment although the patients had a direction for DNR on their chart (or some other form of “living will” or “advance directive” that stated no resuscitation or no “heroic measures”). During the ensuing discussions at these educational sessions, it became clear that some physicians believe that DNR means “Do Not Treat” – which is, of course, an inaccurate interpretation.

Some health practitioners agreed that forms and records systems used in Ontario should be revised to reflect the language used in Ontario legislation, and that this would likely support better practice.

During the meetings with health practitioners as part of this project, several health practitioners in one city told us that local emergency response personnel had been refusing to transport long-term care residents to hospital if the resident's chart had been marked DNR, or "Do Not transport to hospital" had been ticked-off on our level of care form. In these circumstances, emergency response personnel would only transport patients that were "Full Code" to hospital from long-term care. It should be mentioned that at another education session that took place in the same region, a senior manager at Emergency Medical Services (EMS, or ambulance services) was asked about these reports that patients were not being transferred to hospital unless they were documented as "full code," and he stated that no such policy existed.

(e) Who determines capacity?

There was some confusion expressed by health practitioners about who determines capacity for treatment. Some health practitioners were not confident that they knew how to assess the capacity of a patient to make treatment or other health decisions. Some thought that they were required to get a psychiatrist to assess capacity for treatment decision-making. A few health practitioners thought that they would need to get a "Capacity Assessor" to perform this assessment.

ACE and DDO lawyers have also dealt with cases where health practitioners providing care services in long-term care homes have assumed that a person was incapable for treatment if that person had been determined by an "evaluator" (as defined in the *HCCA*) to be incapable for admission to long-term

care. These health practitioners may not have understood that capacity is issue specific and that a person could be capable for some or all treatment decisions although determined incapable for the decision for admission.

(f) Understanding of advance care planning

Health practitioners in our focus groups primarily (and correctly) identified advance care planning as limited to expressing wishes about future treatment. However the description of their practices, or the practices at the institution in which they provided care, illustrated that there was a great deal of confusion about what is informed consent and what is advance care planning.

Health practitioners generally did not connect the identification of a future SDM as part of the advance care planning. Several health practitioners expressed a belief that advance care planning was only applicable to end of life care, and was not related to health care consent.

Some health practitioners believed that any discussion of treatments taking place in the future was advance care planning, even if the treatment was related to a patient's present health condition and could be addressed through consent to a plan of treatment. Other health practitioners thought that any "care planning" was advance care planning, even if these were discussions about treatment options related to a patient's present health condition and their goals of care in the present time.

There appeared to be some confusion on the basic role of "advance care planning" as literature and research documents describe advance care planning

as patient “decision making” or “choices for future medical care” rather than as an expression of “wishes”.

A number of health practitioners did comment that they had not understood the relationship between advance care planning and informed consent, and had never considered how they were connected.

(g) Who can advance care plan?

Some health practitioners did not understand that only a patient can advance care plan. They assumed that any SDM could advance care plan for a patient and could change patient’s expressed capable wishes. Many health practitioners referred to situations where they thought SDMs were advance care planning, and did not understand that in the examples they provided the health practitioner was actually likely obtaining an informed consent from the SDM. This confusion may have resulted from forms that are entitled “advance care plan” or “advance directive” which, in fact, are documenting informed consent.

(h) Communication about consent and advance care planning

A repeated request from health practitioners at our focus groups was for a guide for engaging in communications with patients or SDMs. Although the health practitioners did not necessarily distinguish between discussions about consent and discussions about advance care planning, they expressed interest in guides to improve communications with patients and SDMs, particularly to assist in following the legislative framework. This was usually expressed after an education session explaining consent and advance care planning as detailed in

the *HCCA*. This may also explain why tick-box forms and level of care forms are attractive for health practitioners – they are looking for ‘something’ that can be used as a tool to help them engage in this process in a legally correct way.

Health practitioners talked about how challenging it was to engage in discussion about end-of-life care. They also repeatedly referred to the lack of time available to engage with patients and SDMs to get an informed consent or to assist the patient in engaging in meaningful advance care planning discussions. A point was made by some health practitioners that there is no billing code for such in-depth discussions and, if there were such a code, they might be more disposed to engage in advance care planning.

As an aside, the authors note that Ontario *Schedule of Benefits for Physician Services under the Health Insurance Act*, provides that all insured services will include certain common elements (i.e. that physicians are paid for as part of providing an insured service). These common elements include “obtaining consents” and also “obtaining and reviewing information (including history taking for any appropriate source(s) so as to arrive at any decision(s) made in order to perform the elements of the service”.⁴³⁰ Depending on how advance care planning is operationalized, it may be covered by OHIP.

(i) What to do if no clear consent or advance care planning on Resuscitation

At one site, there was a discussion about CPR and the requirement (or not) to attempt resuscitation. One physician stated that she understood that she was “legally required” to attempt resuscitation on a patient unless there was a

DNR order on the chart. She believed that, even if she had been the patient's physician and was aware that the patient's present condition indicated that resuscitation would not be an appropriate treatment option, unless a DNR order was placed on the chart resuscitation must be attempted. This physician was not aware of her authority to not engage in resuscitation based on her determination that resuscitation would not be clinically appropriate - as is recognized by the *Joint Statement on Resuscitative Interventions*, to which the Canadian Medical Association is a signatory, discussed above.

This is obviously a nuanced issue and a full discussion of this is beyond the scope of this paper. This is included here as an example of the complexity of the relationship between health care consent (including the issue of what treatments are proposed by health practitioners) and advance care planning. This complexity is not recognized by much of the "advance care planning" documentation used in health records. Our observation from several of the sessions is that a number of health practitioners wanted the comfort of paper or "something" on the chart. It did not seem to matter whether what was written on the chart had resulted from a full discussion with the patient or SDM, or was included in a form completed as part of the admission process without being contextualized for the particular patient's health condition.

(j) Patients' wishes

Several health practitioners asked how patient's wishes were to be interpreted by them. These health practitioners appeared to be concerned about

their obligations, if any, when they are aware of a patient's previously expressed wishes. At these sessions, health practitioners were advised that any advance care plans were directions to be interpreted SDMs as part of giving or refusing informed consent (except in emergencies). It was explained that the wishes primarily "speak" to the SDM, not the health practitioners. The health practitioners' obligation was to obtain an informed consent .

This explanation was sometimes met with questions from health practitioners who assumed that any directives (wishes), particularly written advance directives, were required to be followed by the health practitioners as that was what they understood from other materials and education sessions. In one session, this led to a discussion about care planning as distinct from advance care planning. The health practitioners clearly understood that they needed and wanted to assist the patients in planning their care, looking at the options and goals and objectives for treatment related to their present condition. It was concluded at that session that care planning involved discussing the patient's present condition and the likely outcomes for the patient in that context, whereas advance care planning was broader, and did not need to be in context. Advance care planning states "if this happens.. then I want..." even if the precondition was not necessarily something that the patient could expect to occur based on their present health condition.

There was also discussion about whether wishes previously expressed by patients should be used to determine treatment options. Again this led to a

discussion about who interprets wishes, the SDM or the health practitioner. This is a nuanced issue since health practitioners need to understand the patient's needs, lifestyle, wishes and beliefs when doing care planning. However wishes expressed by patients out of context, without complete information on their health condition and options, should not drive what treatment options will be offered in the future.

Another related issue was: what should health practitioners do if they believe that an SDM is not making decisions for the patient in accordance with patient's prior capable and applicable wishes (as required by the *HCCA*). A number of health practitioners were not aware of their option of making an application to the CCB to have the Board determine if the SDM was acting in accordance with the *HCCA*. Some health practitioners stated that such an application would take too much time. They also were unaware of the fact that the *HCCA* requires that such a hearing take place within seven days of being requested or that the *Act* requires a decision be made within one day of the hearing.

(k) Advance care Planning Booklets completed with social worker or volunteer

Many health practitioners expressed concern about finding the time to do advance care planning with patients and their families because of pressures in the health system to do more with less, to serve more patients, and to get things done faster. It was often suggested that social workers or volunteers or other members of the health team should be responsible for doing advance care

planning with patients and their families. In the opinion of the authors, this suggestion illustrates the confusion surrounding the relationship between informed consent, advance care planning, and care planning.

It was suggested by one health practitioner that what was needed was a tick-box form that all patients would complete with a volunteer that outlined care options. He thought that this would save time and money in the health system. When reminded that such a form did not represent an informed consent, this led again to a discussion about the relationship between health care consent and advance care planning.

(l) Influence of materials/ Experts from other Jurisdictions

Some of the confusion about health care consent and advance care planning in Ontario may relate to the fact that the law varies across Canada and across other jurisdictions. As health practitioners in Ontario may have had experience or training in other jurisdictions or read literature and research from these other jurisdictions in the course of their practice, they may not be aware of the details of the legislative differences.

During the discussions, some health practitioners did refer to materials from other jurisdictions, such as the materials from the Fraser Health Authority in British Columbia (discussed above). Some health practitioners also referred to a presentation in the fall of 2013 at Hamilton Health Sciences and Carenet by a physician from California who had created an online tool for patients to use to produce an advance care plan. Although these materials may be applicable for

the jurisdiction in which they were created, they should not be used in Ontario unless adapted and revised to reflect Ontario law. However, some health practitioners commented that such materials were already out there and should just be used here as is. This reflects a lack of knowledge about differences between legislative schemes in different jurisdictions.

(m) Terminology

Many health practitioners commented that terminology on forms, in electronic records, and in materials on consent and advance care planning did not reflect the terminology in the *HCCA*. This was suggested as a primary reason for the confusion about the legal relationship between consent and advance care planning. Some facilities have forms called “advance care plans” that in fact are recording informed consents (assuming the appropriate information is conveyed to the patient before the document is completed). Many forms refer to a patient’s “next of kin” or “POA” rather than the patient’s SDM if he or she should become incapable for making decisions regarding treatment. Health practitioners commented that they frequently ask patients if they have any “advance directives” and were not familiar with the word “wish” and did not necessarily understand that a power of attorney for personal care was a particular kind of “advance directive”. Several health practitioners commented that the use of the words “advance directive” also may be the reason why they look for documents in writing rather than thinking about getting an informed consent.

(n) Criticisms of forms prepared by lawyers

A number of health practitioners expressed criticism of advance care planning documents, particularly statements of wishes, drafted by lawyers. They said that the documents were too vague or overly generalized. In particular, they were critical of statements such as “no heroic measures”. When asked why they were concerned about the wording (when it is primarily the duty of SDMs to interpret and apply wishes) this led to the discussion about the appropriate role of health practitioners who are aware of such wishes, and the requirements to get an informed consent rather than take direction from a document. A few health practitioners thought that there should be a standardized advance care planning form that all patients use, as well as a standardized consent form that all health organizations use, which are each incorporated into the health organizations’ electronic health records.

(o) Where health practitioners look for guidance

At these sessions, the authors asked health practitioners where they look for guidance when they have questions about health care consent and advance care planning. Some participants stated that they would look to their health colleges, insurers, or statements and materials from professional associations (such as the OMA and CMA). A common response was that health practitioners would talk to an ethicist. Few said that they would contact other legal resources

or legal counsel. Few, if any, said that they would look at the *HCCA*, or knew that the legislation was easily available on-line.

2. Seniors

The authors conducted a snapshot focus group with representatives of seniors groups and with individual seniors. The purpose of this focus group was to obtain information on the health care consent process in hospitals and long-term care homes, and also to understand how these stakeholders understood advance care planning and in particular the effect of 'advance directives' and 'living wills'. Of course, this focus group did not attempt to rise to the level of scientific accuracy, but was an attempt to check some of the authors' concerns against the perceptions of these stakeholders.

(a) Health Care Consent

The participants stated that health practitioners generally do not adequately provide options and seek informed consent when seniors' attend hospitals and long-term care homes. The participants noted that the power imbalance between physicians and seniors was significant, and that this affected the ability of seniors to ask appropriate questions relating to the treatments proposed by health practitioners. Many of the participants shared anecdotes of their experiences with the health care system, a common theme of which was that physicians would not seek informed consent to treatment from either patients or SDMs.

(b) Capacity and Substitute Decision-Making

Several of the participants stated that when a senior is transferred to hospital from long-term care they are frequently presumed to be incapable of consenting to treatment. Many of the participants expressed frustration with the fact that health practitioners discuss treatment options with family and friends rather than a capable patient, apparently as a result of the patient's age and appearance.

The participants advised that they, and in their experience other patients, were not aware of the fact that every incapable patient has a default SDM under the *HCCA*. The participants stated that, prior to attending this focus group, they had thought that SDMs had to be appointed pursuant to a formal document for an incapable patient.

(c) Advance Care Planning

Participants reported that seniors are frequently pressured to sign DNR forms on admission to hospital, even before being advised of their current health condition. Participants broke this issue into two parts. First, participants stated that seniors are pressured to begin discussing the issue of DNRs without sufficient information. This group believed younger patients would not be required to participate in this discussion. Second, participants reported that seniors are pressured to positively express a wish that they do not want to be resuscitated, even when they have limited knowledge of their health condition.

Participants were concerned that, in engaging in advance care planning discussions, seniors were not advised of how their expressed wishes would be used in the future. Participants were not aware of the legal framework for implementing advance care planning through SDMs, and expressed concern that their wishes might result in unintended consequences if relied upon inflexibly given uncertain future health conditions.

(d) Recommendations

The seniors' focus group was very supportive of educational initiatives for both patients and health practitioners on informed consent, capacity, substitute decision-making and advance care planning. Participants felt that these issues were so fundamental that the law on health care consent should be taught in high school civics classes.

3. *Lawyers*

The authors conducted a focus group with lawyers practicing health law. We sought to speak both with lawyers who frequently represent and advise health care organizations and with lawyers who frequently represent and advise patients and SDMs.

(a) Health Practitioners' Understanding of Health Care Consent Laws

The participants were asked about their experience of health practitioners' understanding of the laws of informed consent. The participants stated that some health practitioners appear not to fully appreciate, nor have turned their minds to,

issues of informed consent, often until disputes relating to informed consent to treatment have already come to a head with patients and/or family members.

It was the experience of the lawyers surveyed that health practitioners frequently express a belief that an advance directive has the same effect as an informed consent. Several lawyers commented that, in their experience, health practitioners will frequently not speak with a patient or SDM to obtain informed consent where an applicable advance directive is present on the patient's health record.

The participants were also asked about whether health practitioners understand that prior capable wishes can only be implemented through informed consent to treatment from an SDM. The participants were of the opinion that many health practitioners do not understand the legal role of the SDM, or of who should be interpreting wishes, values and beliefs expressed by the patient.

(b) *Can an SDM express Wishes, Values and Beliefs?*

The participants had an interesting discussion on whether an SDM could sign a DNR form expressing wishes on behalf of an incapable patient. The participants noted that there is a fine line between expressing new wishes, values, and beliefs on behalf of a patient, and repeating old wishes, values and beliefs previously expressed by the patient to be recorded in the chart. There was no consensus amongst the lawyers participating in the focus group that an SDM could not legally sign a DNR form expressing wishes on behalf of the patient. The basis for this disagreement was whether a DNR form amounted to

an expression of a new wish, or was simply recording of an old wish expressed by the patient (assuming the patient had expressed a wish not to be resuscitated in the past while capable).

One lawyer also commented that SDMs may be more willing to accurately recount the wishes, values and beliefs of a patient on admission to a hospital, and this may be the reason for having SDMs complete a DNR form early in the patient's admission. This lawyer suggested that having SDMs complete DNR forms at the time of admission may assist physicians with ensuring that SDMs are acting in accordance with their obligations under the *HCCA* (in that they are required to follow an applicable wish), as when the patient's condition worsens SDMs may be reluctant to repeat a patient wish that could result in death.

(c) Advising Patients on completing Powers of Attorney for Personal Care

Many of the lawyers we consulted with frequently advise clients on completing powers of attorney for personal care. We wanted to discuss with these lawyers what they tell clients regarding how wishes expressed in powers of attorney for personal care would be implemented in the future. All lawyers agreed that their standard practice was to advise clients not to express wishes in a power of attorney for personal care. Instead, their standard practice was to advise clients to only designate an attorney for personal care in the document, and to then express wishes orally to their appointed attorney.

The lawyers stated that the basis for this practice was their concern that written wishes expressed in the power of attorney for personal care would,

incorrectly, be considered more binding than later orally expressed wishes. The lawyers also expressed a concern that written phrases may be interpreted as being more inflexible than the client intended.

Participants also commented that the standard legal phrases included in powers of attorney for person care, such as ‘no heroic measures’ and ‘I do not want to be kept alive on machines,’ were incapable of precise application given the breadth of health conditions the client could experience and the evolving health care interventions that could be proposed. The lawyers favoured advising clients to have contextualized and values-based discussions with their designated attorney for personal care. One lawyer stated that the most important question for a client to discuss with his/her SDM was whether the client would want to be kept alive when incapable and without any hope of recovery.

VII. ISSUES IDENTIFIED IN ONTARIO

A. Not enough emphasis on informed consent

In Ontario's legislation, informed consent to treatment has a primacy beyond its role in any of the other jurisdictions' legislation reviewed. Informed consent is both a right of the patient and an obligation of health practitioners. Ontario's legislative scheme favours contextualized patient decision-making and with the exception of a narrowly crafted provision for emergency treatment, requires that a health practitioner and his/her patient (or SDM) discuss the patient's current health condition, treatments, possible alternatives, and the risks and benefits of any treatment proposed.

Advance care planning can only be done by the patient, through the expression of wishes, values and beliefs and/or the designation of an attorney for personal care. With the narrow exception of emergency treatment, patient wishes, values and beliefs can only be given effect through consent to treatment by an SDM.

The *HCCA* provisions on consent to treatment and plans of treatment are carefully tailored to ensure that the patient (or their SDM) cannot legally pre-consent to every potential future treatment. Rather, the patient (or SDM) can only consent to treatment that relates to the patient's current health condition and is likely to occur as a result. Unless there is a plan of treatment in place for an incapable patient to which the patient, when capable, consented (or after the patient became incapable, to which the SDM consented), all other treatments

proposed must go through the SDM, and informed consent to treatment must be obtained (except in an emergency). While the SDM will be tasked with interpreting the prior expressed wishes, values and beliefs of the incapable patient, the applicability of these prior statements must be situated within the patient's current health condition and the information contemporaneously provided to the SDM by a health practitioner.

The recent dialogue in Ontario on advance care planning does not always highlight the most important feature of how health care decisions are to be made: through informed consent to treatment proposed by a health practitioner under the *HCCA*. The current literature largely does not encourage communication between patients, their SDMs and health practitioners about the patient's current health condition, likely prognosis, and the treatments available at the time that treatment is proposed, and instead places emphasis almost exclusively on the time well before treatment is provided. Some advance care planning programs encourage individuals to communicate with their SDMs and health practitioners by stating wishes about what the patient values in life and whether the patient wants to be attached to life-sustaining machines. While early discussions about end-of-life preferences should certainly be encouraged, this is only a first step in the process, and cannot replace a health practitioner's duty to obtain informed consent to a plan of treatment which may include withholding or withdrawal of particular treatments in future. As confirmed by our snapshot focus groups,

health practitioners frequently do not turn their minds to consent to treatment when implementing advance care planning.

Health practitioners, and the guidance provided to them can, in some instances, conflate the decision of what treatment will be *proposed* to the patient and what treatment will be *provided* to the patient into a single treatment decision made jointly by the physician and the patient. This is legally problematic, as the former decision is to be made by the health practitioner in their professional judgment following the standard of care, and the latter decision is to be made by the patient or SDM. We discuss in more detail, below, whether a health practitioner may interpret a patient's wishes, values and beliefs through a process of pre-screening treatment options. While in practice the discussion of proposed treatment and patient consent will occur fluidly, health practitioners and patients should still be cognisant of the fact that two decisions are being made and of their respective legal authority.

Much has been said in Ontario of late on the boundaries of consent to treatment at end-of-life following the decision of the Supreme Court of Canada in *Rasouli*. Physicians may reasonably take the position that a treatment requested by the patient or their SDM will provide no medical benefit, and will thereby not be proposed for the patient (or may submit that the treatment may be withdrawn notwithstanding the ruling in *Rasouli*). While this is certainly an important issue when it arises, it is tangential to the vast majority of end-of-life decisions discussed in this Paper. For many decisions, we understand there are clear

medically appropriate treatments, and the only real issue in dispute is whether these treatments are in the patient's best interests or are covered by an applicable prior capable wish.

The language of international and extra-provincial statutes permeates much of the Ontario discourse on health care consent and advance care planning. Ontario's statutory regime is significantly different from many other jurisdictions – both within and outside Canada. Notably, Ontario did not prescribe a role for health practitioners in directly interpreting and applying advance care plans (except in emergencies). Rather, Ontario chose a highly contextualized scheme for giving or refusing consent to prospective treatment: either the patient can consent to a plan of treatment grounded in his/her current health condition, or the patient can express wishes that are to be interpreted by the patient's SDM in light of the patient's then current health condition if the patient becomes incapable.

This general reluctance to emphasize informed consent to treatment in the context of advance care planning may contribute to the more specific issues identified in Ontario, summarized below.

B. Wishes, values and beliefs must only speak to SDMs

One common issue identified is the belief that patient wishes speak directly to health practitioners. Some health practitioners, and policy documents, even suggest that a written advance directive can be directly implemented for a *capable* patient (i.e. without the need for any contemporaneous discussion with

the patient). While it is rare to find a document containing this error, it nonetheless remains one of the most common misconceptions reported to the authors as part of the focus group process. It would appear that this problem relates to the oversight of some health practitioners, and much of the professional literature, to clarify how 'advance directives' and other advance care planning documents fit into Ontario's legislative scheme for health care consent. Some of these documents may record consent to a plan of treatment (which speaks directly to a physician), but most only record a patient's wishes, values and beliefs and must be interpreted by the patient's SDM as part of the process for obtaining informed consent to determine their applicability.

Importantly, these recorded wishes, values and beliefs can be overridden by any later oral statements. This creates a problem for health practitioners who may be more familiar with the law of jurisdictions where advance directives must be in writing to have full legal effect.

This problem appears to be two-fold. First, many health practitioners do not have sufficient education on the Ontario procedure for obtaining consent to treatment. Second, it is our perception that many health care organizations appear to be increasingly implementing systems and tools for recording advance care planning which do not intrinsically encourage health practitioners to seek informed consent. Some health care organizations that have embraced the concept of advance care planning erroneously rely upon documents that incorporate inappropriate content from other jurisdictions.

C. Health practitioners should not interpret patient wishes to pre-screen treatment options

While closely related to the first issue identified above, this is actually a separate common error of health practitioners, and one that is more likely to be contained in the guiding literature given to health practitioners.

Several policy documents we reviewed suggested that health practitioners should interpret a patient's wishes, values and beliefs before deciding what treatment options to propose. We recognize that this is a nuanced issue. On the one hand, health practitioners should be encouraged to explore a patient's wishes, values, and beliefs with the SDM to ensure that the treatment option selected is in the patient's best interest and/or is in keeping with the patient's applicable wishes. However, health practitioners should not pre-screen the treatment options proposed to the SDM based on how they interpret the patient's prior expressed wishes, values and beliefs – this is the statutory role of the SDM.

The further difficulty with this issue is that it is frequently expressed in the language of the acceptable standard of medical care and medical ethics (i.e. that physicians should only propose treatments that meet the patient's wishes, values and beliefs). While health practitioners should be assisting SDMs to make decisions that either comply with, or consider, the patient's wishes, values and beliefs, in our view treatment options should not be pre-screened by health practitioners. To do so risks that a viable treatment option may not be placed on the table by the health practitioner, whereas referencing it may elicit additional relevant information from the SDM about what the patient would have wanted in

the circumstances. This may also be the case in situations where there are equally ranked SDMs making the treatment decision, and one SDM has additional relevant information about the patient's wishes, values and beliefs. It is also possible that a specific treatment option, if presented, would lead the SDM to choose to make a Form E application to the CCB to depart from the patient's wishes.

D. SDMs cannot advance care plan

While SDMs can consent to a plan of treatment, they cannot express new wishes, values and beliefs on behalf of an incapable patient. As was confirmed through this research project, a frequent mistake by health care organizations (both hospitals and long-term care homes) is to record new wishes, values and beliefs for a patient as expressed by the SDM and to give effect to those wishes outside the process for obtaining informed consent to treatment or a plan of treatment.

As part of the process for giving or refusing consent to treatment, an SDM may discuss with a health practitioner the wishes, values and beliefs of the incapable person. Indeed, it is important for health practitioners to be aware of prior capable wishes in order to comply with their statutory role of questioning whether an SDM is complying with their obligations, and bringing an application to the CCB under s. 37 of the *HCCA*, if necessary.

For example, imagine a situation where an SDM is asked to sign a form stating that dialysis will not be provided to an incapable patient in the future. This executed form could be legally interpreted in four ways:

- (1) The form could record a capable refusal of consent to treatment;
- (2) The form could record an informed consent to a plan of treatment involving the withholding of a particular treatment;
- (3) The form could record a wish, previously expressed by the patient, to not receive a particular treatment; or,
- (4) The form could record a new wish, expressed by the SDM, for the patient not to receive a particular treatment.

The first three options are legally permissible under the *HCCA*, the fourth is not. SDMs can give or refuse consent to treatment on behalf of incapable patients and can recount wishes expressed by the patient to be relied upon by health practitioners in emergencies, and in deciding whether to bring a Form G application to the CCB. However, under no circumstance may SDMs express new wishes on behalf of the patient and have these wishes relied upon by the SDM or health practitioners.

Policies, practices, and forms require clarity when recording statements and decisions by SDMs. Are they providing consent, are they recounting wishes, values and beliefs of the patient, or are they expressing new wishes on behalf of the patient? This is discussed in more detail below in relation to our recommendations.

E. Inappropriate reliance on evidence based research

Another problem that flows from the above identified concerns is the practice of relying upon evidence based research without critically considering whether the best practices proposed are in keeping with Ontario law. We noted this concern above, specifically with regard to the document entitled “Advance Care Planning with Cancer Patients,” which extensively referenced research from other jurisdictions.

While perhaps not indicative of wider knowledge, it is our experience that some health practitioners are surprised to learn that the provisions of the *HCCA* trump the conclusions of more recent advance care planning evidence based research. In one instance, it was the authors’ experience that a health practitioner appeared to believe that, since the *HCCA* was enacted in 1996, more recent practice guidelines should be followed – even though they did not comply with the consent provisions of the *HCCA*. While this is an extreme opinion, we have observed some health practitioners and organizations relying upon medical recommendations (with legal implications) from other jurisdictions where advance care planning is not so closely connected with informed consent.

This is, of course, not a criticism of evidence-based medicine. But, it highlights the need to guard against relying upon evidence-based medicine with a medico-legal component without first critically exploring differences in the legal structure of the jurisdiction where this research originates.

VIII. RECOMMENDATIONS

This section sets out the authors' recommendations to address the issues identified in the immediately preceding section.

A. Guiding Principle: Contextualizing Health Care Decisions

Ontario law is somewhat unique (or at least is near one end of a spectrum) in its emphasis on obtaining consent for proposed treatment from an SDM even where a patient has engaged in formalized advance care planning. "Best practices" and clinical tools cross borders easily and instantly (especially now that they are available on-line), and the proliferation of extra-jurisdictional forms and policies appears to have influenced practices in Ontario. The bottom line is that forms, tools, and policies that may work in many other jurisdictions may be legally incorrect (or incomplete) in Ontario when adopted without revision.

As we have repeated many times in this Paper, with the exception of emergency treatment, Ontario law only allows patient wishes, values and beliefs to be implemented through the law of informed consent to treatment. While some jurisdictions allow advance directives to speak directly to health practitioners (for example, Alberta and Nova Scotia allow health practitioners to take direction from a personal directive where an applicable directive does not appoint an agent), Ontario law favours contextualized decision-making to a greater extent by ensuring that either patients or, if incapable, their SDMs give informed consent before treatment is provided.

The authors do not recommend any changes to this aspect of Ontario law. This law provides an appropriate balance between the interests of the patient in directing future care on the one hand, and on the other hand the risks associated with being confined by inapplicable written wishes, the pitfalls of legal drafting, and the vagaries of future health conditions. Ontario law is also supportive of health practitioners who (with the exception of emergencies) are not required to interpret nebulously drafted legal documents and can take direction from a real-life discussion with an SDM. Health practitioners are also protected from liability where they act reasonably and in good faith upon informed consent for incapable patients given by SDMs.

In our view, Ontario law is sound, but it is not always matched in its application at the front line. The goal of these recommendations is to encourage health practitioners and health care organizations to emphasize contextualized patient decision-making over rote recording and application of wishes, values and beliefs. While there will, and should always be, opportunities for patients to express wishes, values and beliefs about future care, more emphasis should be put on the interpretation of these statements by an SDM as part of obtaining informed consent to treatment. Similarly, more emphasis should be placed on obtaining informed consent to a plan of treatment governing future care related to a patient's present condition, rather than simply recording the patient's wishes. These recommendations are discussed in more detail below.

Our recommendations are aimed at encouraging contextualized patient decision-making.

B. First Recommendation: Give Priority to Consent to Treatment

Too often, health practitioners solicit patients to engage in advance care planning when consent to a treatment or a plan of treatment could (and likely should) be obtained. Perhaps for reasons of expediency, health practitioners opt to record patients' wishes, values and beliefs, rather than have in-depth discussions with patients about their present health problems, the health problems that they are likely to have in the future given their current health conditions, and the future treatments that are available to address these health problems. Moreover, some health practitioners seem not to always give appropriate consideration to the uses that will, and legally may, be made of expressed wishes, values and beliefs in the future.

Under Ontario law, prior expressed wishes, values and beliefs are intended to guide the SDM in giving or refusing informed consent to treatment. Unfortunately, many health practitioners appear not to understand this aspect of Ontario law and believe the recording of advance directives to be a sufficient and complete step.

Where the risks and benefits of treatments connected to the patient's current health condition are known, it would be preferable for health practitioners to seek consent to or refusal of a treatment or plan of treatment from a patient (or their SDM). In many cases, utilizing the plan of treatment provisions in the *HCCA* would limit the need to rely upon prior capable wishes in deciding whether to provide emergency treatment. This would, at least conceptually, lead to more

authentic decision-making and reduce the stresses associated with treatment decisions made in emergency situations.

Institutional and regulatory policies and practices should encourage health practitioners to seek consent to a plan of treatment to the greatest extent possible before soliciting wishes, values and beliefs. While a process that emphasizes the importance of knowing the general wishes of a patient is important, more education is needed about closing the loop by seeking informed consent to a proposed treatment, rather than relying on wishes alone. While this could also be addressed legislatively, we have decided not to propose legislative reform to address this issue as it is doubtful, based on our learnings here, that legislative reform would address the operationalization of consent at the front line.

For the ease of the reader, we have prepared the below draft language as an example of what might be incorporated into health care organizations' policies, as well as an example of how this policy might work in practice:

Policy

(1) Treatment Related to the Patient's Present Health Condition

Before initiating a planned conversation with a capable patient to discuss his/her wishes, values, and beliefs in relation to future treatment(s) (also known as advance care planning), a health practitioner shall consider the extent to which future treatment(s) can be governed by an informed consent to treatment (or plan of treatment) relating to the patient's present health condition.

For any future treatment(s) relating to the patient's present health condition, a health practitioner shall seek the patient's informed

consent to, or refusal of, such treatment(s) by advising the patient of information about each of the below matters that a reasonable person in the same circumstances as the patient would require in order to make a decision (informed consent or refusal) about the treatment(s):

1. The nature of the treatment.
2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.

A health practitioner shall also provide responses to any requests by the patient for additional information about the above matters.

Nothing in this policy should be interpreted as limiting the right of patients to express wishes, values and beliefs at any time to guide future care and to have these recorded by health practitioners. This policy is intended to guide health practitioner initiated processes for health care consent and advance care planning.

(2) Treatment Beyond the Patient's Present Health Condition

Where all available and clinically indicated informed consents and refusals have been obtained from the patient in relation to treatment(s) relating to the patient's present health condition, a health practitioner may then proceed to solicit the patient's wishes, values and beliefs in relation to other treatments (i.e. advance care planning).

(3) Summary of Policy

First, discuss treatment(s) relating to the patient's present health condition and seek informed consent to the treatment(s) or plan of treatment from the capable patient (or if incapable, the SDM).

Second, where informed consent (or refusal) cannot be obtained because treatment(s) to be discussed do not relate to the patient's present health condition, health practitioners may assist the patient to advance care plan through soliciting the patient's wishes, values

and beliefs. These may only be obtained from the capable patient, not the SDM.

Example:

Ms. Jones is a patient recently admitted to a long-term care home. Dr. Singh is a physician practicing at the home. Pursuant to the home's policies, a health practitioner is required to discuss and document whether Ms. Jones wants to be transferred to a hospital to receive particular treatments in the future.

Before requesting Ms. Jones' wishes, values and beliefs about treatments in a hospital, Dr. Singh should first consider Ms. Jones' present health problems and the health problems that Ms. Jones is likely to have in the future given her current health condition. Dr. Singh should then seek Ms. Jones's informed consent or refusal to a plan of treatment relating to transfer to hospital for treatment(s) related to Ms. Jones' current health problems or the health problems her current health condition make likely.

After exhausting the clinically recommended treatment options relating to Ms. Jones' present health condition (for which informed consent may lawfully be given), Dr. Singh may proceed to solicit Ms. Jones' wishes, values and beliefs in relation to other hospital-based treatments, as necessary.

We accept that it may not always be easy to tell which treatments relate to a patient's present health condition, and which do not. The limits of informed consent to treatment (or a plan of treatment) are factual questions to be determined for each patient on the basis of clinical knowledge relating to potential treatments, the patient's current health problems, and the patient's likely future health problems based on his/her present health condition. Our goal is to prepare a framework that prioritizes obtaining consent to treatment over rote solicitation of wishes, values and beliefs.

We recommend that institutional and regulatory policies and forms require that health practitioners utilize consent to plans of treatment

for all proposed treatments relating to the patient's present health condition (as more fully set out in the plan of treatment provisions in the HCCA) before soliciting patient wishes, values and beliefs for future care.

C. Second Recommendation: Clarified Advance Care Planning Model addressing relationship with Health Care Consent

Our second recommendation is for the relationship between health care consent and advance care planning under Ontario law to be clarified for health practitioners. Closely connected with this recommendation is our proposal that the language used in health care consent and advance care planning policies, forms, and tools be harmonized with the terminology used in Ontario legislation. Forms, policies and guidelines should also expressly distinguish between the process of obtaining consent to treatment, and the process of recording patient wishes, values and beliefs.

In the opinion of the authors, “health care consent” and “advance care planning” should be thought of as a single process, divided into three parts:

1. Identifying the SDM

The health practitioner should discuss with the capable patient the hierarchy of decision-makers under the *HCCA* to determine whether the patient is satisfied with their default SDM in the event he/she becomes incapable of giving or refusing consent. The patient should be advised that, if dissatisfied with their default SDM, the patient may (if capable to do so under the *SDA* provisions governing powers of attorney) create a power of attorney for personal care designating an attorney (or attorneys) who will rank ahead of the default family member SDMs.

While specifically not providing legal advice, health practitioners should explain the rules governing substitute decision-making to patients. Similarly, health practitioners should not provide legal advice to patients on drafting powers of attorney for personal care, but should refer patients to available resources explaining how to designate an attorney for personal care.

2. Recording of prior capable wishes, values and beliefs

The health practitioner should discuss with the capable patient the patient's wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent for the specific treatments discussed. These are possible treatment options that are not related to the patient's present health condition (which should be addressed through health care consent from the capable patient) This discussion may be geared toward a particular health condition, or may be a broader discussion about messages that will help a future SDM determine how the patient would make decisions for him or herself.⁴³¹

The health practitioner should be careful not to solicit highly specific, yet clinically uninformed, wishes with respect to future treatments that may categorically bind future SDMs. Rather, health practitioners should focus on more general wishes, and should encourage the patient to communicate directly with their SDM.

3. Obtaining Health Care Consent

Health care consent is not commonly considered in tandem with advance care planning but, in the opinion of the authors, should be. Too often, advance care planning is conceptualized as rote collection and recording of prior capable wishes, without attention to how those wishes will be acted upon in the future.

Health practitioners should recognize that informed consent to treatment is still required from the capable patient (or the incapable patient's SDM) even if an advance care plan exists (except in an emergency). Health practitioners should not pre-screen treatment options based on their own interpretation of the patient's wishes, values, and beliefs, but should instead propose a full list of options to be narrowed through discussions with the patient or SDM. Health practitioners have an obligation to explain to the SDM their statutory role and obligations to the patient.

Health practitioners should recognize that SDMs cannot express new wishes, values and beliefs on behalf of the patient. Health practitioners should also recognize that they must assess whether the SDM is complying with his/her obligations to the patient, and bring an application to the CCB if necessary.

Fundamentally, we are suggesting closing the loop on advance care planning. The current practice in Ontario has advance care planning front-loaded to the point where the 'back-end' consideration of patient wishes, values, and

beliefs appears to be secondary to their ‘front-end’ expression. More emphasis should be placed on advance care planning at the ‘back-end’: i.e., to the contextualized informed consents or refusals of SDMs (if the patient is incapable).

We should explain how the above model for health care consent and advance care planning relates to our first recommendation on giving priority to plans of treatment. In the authors’ opinion, the recording of prior capable wishes (part 2 above) should occur after consents to (and refusals of) treatments relating to the patient’s present health condition have been exhausted. Identification of the SDM and health care consent from an SDM (parts 1 and 3 above) may occur at any clinically indicated time. However, the above model for health care consent and advance care planning is not dependant on our first recommendation being accepted or implemented.

We recommend conceptualizing health care consent with advance care planning as a three part process involving the:

- (1) Identifying the SDM by the capable patient;*
- (2) Recording wishes, values, and beliefs expressed by the patient when capable; and,*
- (3) Obtaining health care consent from the SDM.*

D. Third Recommendation: Use Terminology in HCCA

Health practitioners, and institutional policies and forms should use the language expressed in the *HCCA* when seeking health care consent and engaging in advance care planning. When engaging in advance care planning,

the use of language such as 'directions,' 'decisions' and 'living wills' should be discouraged in Ontario. Similarly, the term 'Advance Directive' should not be used in Ontario on health care forms, institutional policies, or in discussions with patients. These terms would appear to be transplanted from other jurisdictions where, for example, an advance directive or a living will, are specific documents that 'direct' treating health practitioners. The use of these terms could lead patients, SDMs and health practitioners to misunderstand Ontario's legislative scheme for giving and refusing informed consent.

We recommend that terminology used in health care consent and advance care planning forms, tools, and policies track the language in the HCCA, and that these documents should expressly distinguish between consent and the recording of wishes, values, and beliefs.

E. Fourth Recommendation: Revise the HCCA to make advising the SDM of his/her rights and obligations part of informed consent

We believe that more informed and involved SDMs could go a long way toward ensuring that health care practice embodies Ontario's legislative balance between health care consent and advance care planning. With knowledge of their role to interpret and apply prior capable wishes, and to make decisions in the patient's best interests, active SDMs could help health practitioners ensure that advance care planning tools and forms are used appropriately, and that informed consent is obtained. In the experience of the authors, and as borne out by our focus groups, SDMs are sometimes unaware of the principles upon which they are to make health care decisions for incapable patients.

From a practical perspective, the best way to ensure that SDMs obtain the information they need to make decisions on behalf of incapable patients is for health practitioners to provide this information. The Ontario Court of Appeal has already recognized an obligation on health practitioners to inform SDMs of their decision-making obligations before providing treatment.⁴³² However, it is our experience, as confirmed in focus groups, that health practitioners are unlikely to be aware of this obligation. We recommend codifying this obligation in statute, incorporating the health practitioners' obligation to inform SDMs of their decision-making obligations into the requirement for health care consent to be informed. In short, where an SDM is giving or refusing consent on behalf of an incapable patient, we recommend that, in addition to health practitioners' current statutory obligation to obtain informed consent, health practitioners also be statutorily obliged to inform SDMs of their role (recognizing that this could be done by simply providing a plain language pamphlet). Where health practitioners fail to comply with this requirement, a consent obtained from an SDM will not be lawfully obtained, with all of the same consequences as currently exist at law.

From a conceptual perspective, we believe incorporating this obligation into informed consent makes sense. Just as patients should be given the opportunity to understand the risks and benefits of treatment, SDMs should be given the opportunity to understand the test they should apply in considering these risks and benefits. We also believe that the proposed consequences of failing to inform an SDM of his/her obligations (i.e. vitiating informed consent), will

be taken seriously by health practitioners and make voluntary compliance more likely. The mechanisms for doing so need not be highly complex – a plain language guide for SDMs would go a long way to at least apprise SDMs of the framework for providing health care consent in Ontario.

Legislatively, we provide an example of how this amendment could be given effect in the *HCCA* with respect to consent to treatment (proposed new text is underlined):

No treatment without consent

10. (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,

(a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or

(b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this Act. 1996, c. 2, Sched. A, s. 10 (1).

Opinion of Board or court governs

(2) If the health practitioner is of the opinion that the person is incapable with respect to the treatment, but the person is found to be capable with respect to the treatment by the Board on an application for review of the health practitioner's finding, or by a court on an appeal of the Board's decision, the health practitioner shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless the person has given consent. 1996, c. 2, Sched. A, s. 10 (2).

Elements of consent

11. (1) The following are the elements required for consent to treatment:

1. The consent must relate to the treatment.
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud. 1996, c. 2, Sched. A, s. 11 (1).

Informed consent

- (2) A consent to treatment is informed if, before giving it,
- (a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
 - (b) the person received responses to his or her requests for additional information about those matters. 1996, c. 2, Sched. A, s. 11 (2).

Same

- (3) The matters referred to in subsection (2) are:
1. The nature of the treatment.
 2. The expected benefits of the treatment.
 3. The material risks of the treatment.
 4. The material side effects of the treatment.
 5. Alternative courses of action.
 6. The likely consequences of not having the treatment. 1996, c. 2, Sched. A, s. 11 (3).

Express or implied

- (4) Consent to treatment may be express or implied. 1996, c. 2, Sched. A, s. 11 (4).

Information to Substitute Decision-Maker

(5) Where a person is incapable with respect to a treatment, in addition to the items set out in subsection (2), a consent to the treatment will be informed under subsection (1) only if, before giving or refusing consent to the treatment on the person's behalf, the substitute decision-maker received information regarding the principles for giving or refusing consent set out in section 21 and received information on applications to the Board under sections 32 to 37.1.

Similar legislative provisions would have to be drafted in order to mandate a parallel obligation on health practitioners to inform SDMs of their obligations in giving or refusing consent to admission to care facilities and/or personal assistance services.

As set out in the above proposed legislative amendment, we also believe that SDMs should receive information on applications to the CCB so that they will be aware of the option to apply for directions, to depart from an applicable prior capable wish, etc.

We recommend that the HCCA be amended to codify the requirement that SDMs be informed of their decision-making obligations, and to also require that SDMs be informed of the availability of the CCB, before giving or refusing informed consent to treatment on behalf of an incapable patient.

F. Implementing these Recommendations

We recommend a comprehensive education program for all health practitioners, with a specific emphasis on those practicing in hospitals, long-term care homes, and retirement homes, as well as community agencies, providing training on the Ontario law of informed consent to treatment and its relationship to advance care planning. This educational program should be tied to funding of health care organizations.

It is beyond the scope of this paper to illustrate the various ways in which this recommendation could be implemented. However, as an example, this recommendation could be implemented by through:

- Health regulatory colleges;
- Regulations under the *Excellent Care for All Act*⁴³³ provisions relating to Quality Improvement Plans (QIPs):
 - These have applied for some time to public hospitals, now apply to community care access centres, and in 2015, will apply to long-term care homes – for primary care settings such as community health centres and family health teams, QIPS are mandated by the

local health integrated networks (“LHINs”) through their multi-sector service accountability agreement, the “M-SAA”); and,

- LHINs
 - Via multi-LHIN educational initiatives (so as not to duplicate effort and resources by creating different tools); or
 - As with the community health centres and family health teams’ QIPs, using the applicable LHIN service accountability agreements such as the H-SAA for hospitals and L-SAA for long-term care homes, to enshrine accountability for such education.

These educational programs could also be enforced through accreditation bodies, such as Accreditation Canada, whose standards for service providers to the seniors’ population relating to advance care planning currently contains some of the legal misstatements identified in this Paper:

- 7.3 The organization works with service providers to provide information on advance care planning.

Guideline

An advance care directive (or living will or personal directive) is a set of instructions given by individuals that specify which actions are to be taken in the event that they are no longer able to make their own decisions due to illness or incapacity. An advance care directive also appoints a person to make decisions on their behalf. Information on advance care planning includes advice on how to make an advance care plan, appoint a substitute decision-maker, and communicate advance care wishes to family, friends and service providers.⁴³⁴ [Emphasis added]

The above standard set for service providers to seniors suggests that an advance care directive is a “set of instructions” specifying what actions are to be taken – rather than wishes to be interpreted by the SDM. These standards are in need of revision with regard to Ontario law, and we recommend that accreditation be tied to educational programs on health care consent and advance care planning.

GLOSSARY

Advance Care Planning

A generic term used across many jurisdictions to describe the process of planning by an individual for a time when he or she no longer has the mental capacity to make decisions about health care. Advance care planning is comprised of two elements:

- (1) Selection of the individual who will make decisions for the patient in the event the patient becomes incapable (sometimes referred to as a “Proxy Directive,” as the patient is designating their proxy decision-maker – referred to as the SDM in the *HCCA*); and,
- (2) Expression of wishes, values, and beliefs about future health care decisions to be made in the event the patient becomes incapable (sometimes referred to as the “Instructional Directive,” as the patient is giving instructions about future care – referred to as “wishes” in the *HCCA*).

Advance Directive

A generic term used in Ontario to refer to specific communications from patients containing the patient’s express wishes regarding health care choices in the future. In the *HCCA*, these wishes may be communicated orally, in writing, or by alternative means. However, in many other jurisdictions this phrase refers instead to a formal document providing directions to a health practitioner and substitute decision-maker. The term “Advance directive” is also sometimes used beyond the expression of wishes, values, and beliefs (instructional directives) to refer to the designation of a substitute decision-maker (a proxy directive). Under the *SDA* and *HCCA*, a proxy directive would be a power of attorney for personal care designated an attorney for personal care. A power of attorney for personal care may also include wishes, values and beliefs.

Agent

A legal term used in this Paper, in the broadest sense, to refer to the individual appointed by the patient to make health care decisions on the patient’s behalf. Under the *HCCA*, the patient’s agent would be his/her SDM.

Assessor (commonly referred to as a “Capacity Assessor”)

Means a member of the:

1. College of Physicians and Surgeons of Ontario.

2. College of Psychologists of Ontario.
3. Ontario College of Social Workers and Social Service Workers and holding a certificate of registration for social work.
4. College of Occupational Therapists of Ontario.
5. College of Nurses of Ontario and holding a general certificate of registration as a registered nurse or an extended certificate of registration as a registered nurse,

who has complied with the requirements set out in regulation, as quoted below:

Persons qualified to do assessments of capacity

2. (1) A person is qualified to do assessments of capacity if he or she,

(a) satisfies one of the conditions set out in subsection (2);

(b) has successfully completed the qualifying course for assessors described in section 4;

(c) complies with section 5 (continuing education courses);

(d) complies with section 6 (minimum annual number of assessments); and

(e) is covered by professional liability insurance of not less than \$1,000,000, in respect of assessments of capacity, or belongs to an association that provides protection against professional liability, in respect of assessments of capacity, in an amount not less than \$1,000,000. O. Reg. 460/05, s. 2 (1).

(2) The following are the conditions mentioned in clause (1) (a):

1. Being a member of the College of Physicians and Surgeons of Ontario.

2. Being a member of the College of Psychologists of Ontario.

3. Being a member of the Ontario College of Social Workers and Social Service Workers and holding a certificate of registration for social work.

4. Being a member of the College of Occupational Therapists of Ontario.

5. Being a member of the College of Nurses of Ontario and holding a general certificate of registration as a registered nurse or an extended certificate of registration as a registered nurse. O. Reg. 460/05, s. 2 (2).

(3) The requirement that the person hold a general certificate of registration as a registered nurse or an extended certificate of registration as a registered nurse, as set out in paragraph 5 of subsection (2), does not apply to a member of the College of Nurses of Ontario who, on November 30, 2005, is qualified to do

assessments of capacity under Ontario Regulation 293/96 (Capacity Assessment) made under the Act. O. Reg. 460/05, s. 2 (3).

(4) Clause (1) (b) does not apply to a person who, on November 30, 2005, is qualified to do assessments of capacity under Ontario Regulation 293/96 (Capacity Assessment) made under the Act. O. Reg. 460/05, s. 2 (4).⁴³⁵

Attorney for Personal Care

An attorney under a power of attorney for personal care given under the *Substitute Decisions Act, 1992*.⁴³⁶

Best Interests

The *HCCA* sets out the following considerations that must be considered as part of determining the patient's best interests:

21(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;

(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and

(c) the following factors:

1. Whether the treatment is likely to,

i. improve the incapable person's condition or well-being,

ii. prevent the incapable person's condition or well-being from deteriorating, or

iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.⁴³⁷

Capacity

Under the *HCCA*, a person is capable with respect to treatment, admission to a care facility or personal assistance services if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.⁴³⁸

Default SDM

The individual authorized to make a particular health care decision on behalf of an incapable patient under the *HCCA*, where the incapable patient has not otherwise selected an individual to make that health care decision.

Emergency

There is an emergency if the person for whom the treatment is proposed is apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm.⁴³⁹

Evaluator

Means, in the circumstances prescribed by the regulations [under the *HCCA*],

- (a) a member of the College of Audiologists and Speech-Language Pathologists of Ontario,
- (b) a member of the College of Dietitians of Ontario,
- (c) a member of the College of Nurses of Ontario,
- (d) a member of the College of Occupational Therapists of Ontario,
- (e) a member of the College of Physicians and Surgeons of Ontario,
- (f) a member of the College of Physiotherapists of Ontario,
- (g) a member of the College of Psychologists of Ontario,

(h) a member of a category of persons prescribed by the regulations as evaluators,⁴⁴⁰ or,
a member of the Ontario College of Social Workers and Social Service Workers.⁴⁴¹

Grantor

A legal term referring to an individual who has granted legal rights and responsibilities to another individual – such as an individual granting authority under a power of attorney for personal care to a substitute decision-maker.

Guardian with authority for personal care

A guardian of the person appointed under the *Substitute Decisions Act, 1992*, where the terms of the guardianship order grant the guardian authority to make personal care decisions.

Health Care

A broad term used in this paper to refer to all decisions made for a health-related purpose, including decisions about treatment, admission to a care facility, and personal assistance services in a care facility.

Health Practitioner

Means a member of an Ontario health regulatory college governing the following health professions under the *Regulated Health Professions Act*:

Audiology and Speech-Language Pathology
Chiropractic
Chiropractic
Dental Hygiene
Dental Technology
Dentistry
Denturism
Dietetics
Kinesiology
Massage Therapy
Medical Laboratory Technology
Medical Radiation Technology
Medicine
Midwifery
Nursing
Occupational Therapy
Opticianry
Optometry
Pharmacy

Physiotherapy
Psychology
Respiratory Therapy
Traditional Chinese Medicine⁴⁴²

and also means a naturopath registered as a drugless therapist under the *Drugless Practitioners Act* or a member of a category of persons prescribed by the regulations as health practitioners.⁴⁴³

Instructional Directive

A broad term referring to expressions of wishes, values, and beliefs made by the patient about future health care decisions to be made in the event the patient becomes incapable.

Patient

In this Paper, we use the term “patient” in the broadest sense, to include any individual for whom treatment is proposed; this may include residents of long-term care homes and clients of other health care organizations. It also includes “person” as that term is used in this Paper.

Personal Care

A broad term encompassing health care, nutrition, shelter, clothing, hygiene or safety, as defined under the *SDA*.⁴⁴⁴

Plan of Treatment

Means a plan that,

- (a) is developed by one or more health practitioners,
- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person’s current health condition, and
- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person’s current health condition.⁴⁴⁵

Power of Attorney for Personal Care

A formal written document under the *Substitute Decisions Act, 1992* appointing an attorney for personal care, which may also give instructions to that attorney.

Principal

A legal term, referring to the person on whose behalf decisions are made by an agent. In some jurisdictions, a patient-appointed substitute decision-maker is referred to as an agent in legislation.

Prior Capable Wish

Under the *HCCA*, a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age.⁴⁴⁶

Proxy

A term used in the broadest sense in this paper to refer to the individual selected by the patient to make decisions for the patient.

Proxy Directive

A term used in the broadest sense in this paper to refer to a statement selecting the individual who will make health care decisions for the patient in the event the patient becomes incapable

SDM (Substitute Decision-Maker)

A term used in the broadest sense in this Paper to refer to any individual making health care decisions on behalf of another individual.

Treatment

Under the *HCCA*, treatment means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan, but does not include,

- (a) the assessment for the purpose of this Act of a person's capacity with respect to a treatment, admission to a care facility or a personal assistance service, the assessment for the purpose of the *Substitute Decisions Act, 1992* of a person's capacity to manage property or a person's capacity for personal care, or the assessment of a person's capacity for any other purpose,
- (b) the assessment or examination of a person to determine the general nature of the person's condition,
- (c) the taking of a person's health history,

- (d) the communication of an assessment or diagnosis,
- (e) the admission of a person to a hospital or other facility,
- (f) a personal assistance service,
- (g) a treatment that in the circumstances poses little or no risk of harm to the person.⁴⁴⁷

ENDNOTES

¹ In this Paper, we use the term “patient” in the broadest sense, to include any individual for whom treatment is proposed; this may include residents of long-term care homes and clients of other health care organizations. It also includes “person” as that term is used in this Paper. Further, where we refer to “patient”, it is understood that this means either the capable patient, or if the patient has been found incapable to consent to the proposed treatment, his/her SDM as determined under s. 20 of the *Health Care Consent Act, 1996*, S.O. 1996, c. 2 Sched. A (*HCCA*).

² We should also note that there are statutory exceptions to the requirement to obtain informed consent, such as for time-limited periods where an individual has been found unfit to stand trial in a criminal matter (see *Criminal Code*, RSC 1985, c C-46 s. 678.58) or where an individual is infected with an agent of a communicable disease that is a virulent disease and has failed to comply with an order of a medical officer of health (see *Health Protection and Promotion Act*, RSO 1990, c H.7, s. 35).

³ *HCCA*, note 1.

⁴ The authors wish to thank the Ontario Hospital Association (“OHA”), the Ontario Association of Non-Profit Homes & Services for Seniors (“OANHSS”) and the Ontario Long-Term Care Association (“OLTCA”) for their assistance in facilitating requests of their members for relevant materials.

⁵ *Starson v. Swayze.*, 2003 SCC 32, [2003] 1 S.C.R. 722 at 759.

⁶ Stephen V. Fram, *Final Report of the Advisory Committee on Substitute Decisions Making for Mentally Incapable Persons* (Toronto: Guardianship & Advocacy Review Committee, 1987) 42, 45.

⁷ Fram, note 6, 42.

⁸ Fram, note 6, 44.

⁹ *Cuthbertson v. Rasouli*, 2013 SCC 53 at para. 18 [*Rasouli*].

¹⁰ *Malette v. Shulman* (1990), 72 OR (2d) 417, 1990 CarswellOnt 642, (CA) at para. 45.

¹¹ *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (C.A.); see also Janet Dunbrack, “Advance care planning: the Glossary project, Final Report”, (Ottawa: Health Canada, August 22, 2006), 20, online: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-proj-glos/2006-proj-gloss-eng.pdf (Last accessed December 11, 2013); Daniel L. Ambrosini, Anne G. Crocker, Eric Latimer, “Preferences for Instructional or Proxy Directives in Mental Health: An Exploratory Mixed Methods Study” 2012 JEMH Vol. 6.

¹² Fram, note 6, 253.

¹³ Fram, note 6, 288.

¹⁴ Educating Future Physicians in Palliative and End-of-Life Care, “Facilitating Advance Care Planning: An Interprofessional Education Program” 33-34, online: EFPPEC, http://www.afmc.ca/efppec/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf

(Last accessed December 11, 2013) (EFPPEC).

¹⁵ See for example *Male v. Hopmans*, [1967] 2 O.R. 457 (Ont CA).

¹⁶ *Nelitz v. Dyck* (2001), 52 OR (3d) 458, 2001 CarswellOnt 27.

¹⁷ *Allan v. New Mount Sinai Hospital* (1980), 109 D.L.R. (3d) 634, 28 O.R. (2d) 356 (H.C.J.) at paras. 28, 34, rev'd on other grounds (1981), 125 D.L.R. (3d) 276 (Ont. C.A.).

¹⁸ CED, (Ontario 4th) vol 31, title 80 "Hospitals and Health Care", at §121-122, see also Ellen I. Picard and Gerald B. Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 4th edition, (Toronto: Thomson Carswell LLP, 2007), 41-54; John J. Morris and Cynthia D. Clarke, *Law for Canadian Health Care Administrators*, 2nd Edition (Markham, Ontario: LexisNexis, 2011), 189-190.

¹⁹ *Halsbury's Laws of Canada*, 2013 reissue (LexisNexis Canada Inc., 2013) "Medicine and Health – III Consent to Treatment" (Contributor: Ayanna Ferdinand). Online: Quicklaw, www.lexisnexis.com; *Ciarlariello v. Schacter*, [1993] 2 S.C.R. 119.

²⁰ Timothy Caufield, "Revising Core Principles: Autonomy, Consent, and the Biobanking Challenge" in Jocelyn Downie & Elaine Gibson, eds. *Health Law at the Supreme Court of Canada* (Canada: LexisNexis, 2007), 169,170.

²¹ *Malette v. Shulman*, note 10, para. 18.

²² *Hopp v .Lepp*, [1980] 2 SCR 192 (QL).

²³ *Reibl v. Hughes*, [1980] 2 SCR 880 (QL).

²⁴ Lorne E. Rozovsky, *The Canadian Law of Consent to Treatment*, 3d ed (Canada: LexisNexis, 2003), 161.

²⁵ *Reibl v. Hughes*, note 23, 4; *Hopp v. Lepp*, Note 23, 11-12; Rozovsky, note 24, 161.

²⁶ Rozovsky, note 24, 162.

²⁷ Rozovsky, note 24, 161.

²⁸ Rozovsky, note 24, 162.

²⁹ Rozovsky, note 24, 163.

³⁰ *Rasouli*, note 9, paras. 18-21.

³¹ *Stell v. Obedkoff*, [2000] O.J. No. 4011 (S.C.J.), para. 201.

³² *Young v. Wellesley Hospital*, [1994] O.J. No. 1341 (S.C.J.), paras. 122-123; *Laurie v. Parham*, 2010 MBCA 62, paras. 65-82. See also *Flora v. Ontario (Health Insurance Plan, General Manager)*, 2008 ONCA 538 – discussing denial of OHIP funding.

³³ *HCCA*, note 1, s. 10.

³⁴ *HCCA*, note 1, s. 11(4).

³⁵ *HCCA*, note 1, s. 11(1).

³⁶ *HCCA*, note 1, s. 11(2)-(3).

³⁷ *HCCA*, note 1, s. 12.

³⁸ *HCCA*, note 1, s. 14.

³⁹ *HCCA*, note 1, s. 2 “plan of treatment”.

⁴⁰ *HCCA*, note 1, s. 12.

⁴¹ *Rasouli*, note 9.

⁴² *HCCA*, note 1, s. 2(1).

⁴³ *Rasouli*, note 9, para. 68.

⁴⁴ *Rasouli*, note 9, para. 70.

⁴⁵ *HCCA*, note 1, ss. 25(3)(e), 26.

⁴⁶ *HCCA*, note 1, s. 29(4).

⁴⁷ *HCCA*, note 1, s. 27.

⁴⁸ *HCCA*, note 1, s. 25(5)-(9).

⁴⁹ *HCCA*, note 1, s. 25(5)-(9).

⁵⁰ *HCCA*, note 1, s. 2(1).

⁵¹ *HCCA*, note 1, s. 40.

⁵² *Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8, ss. 44(11)(d), 46-47.

⁵³ *HCCA*, note 1, s. 47.

⁵⁴ *HCCA*, note 1, s. 2(1).

⁵⁵ *HCCA*, note 1, ss. 2(1) definition of “recipient,” 57-58.

⁵⁶ *HCCA*, note 1, s. 4(2).

⁵⁷ *HCCA*, note 1, s. 4(3).

⁵⁸ *HCCA*, note 1, s. 29.

⁵⁹ *Starson*, note 5, 759.

⁶⁰ *HCCA*, note 1, s. 4(1).

⁶¹ *HCCA*, note 1, s. 15.

⁶² *Starson*, note 5, at 761-763.

⁶³ *HCCA*, note 1, s. 17.

⁶⁴ College of Physicians and Surgeons of Ontario, *Consent to Medical Treatment, Policy Number: #4-05* (February 2006), 6-7, online: College of Physicians and Surgeons of Ontario, <http://www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/Consent.pdf> (Last accessed: October 15, 2013) (*Consent Policy*).

⁶⁵ *Mental Health Act*, R.S.O. 1990, c. M.7 s. 59 (note also that rights advice is given to the individual for whom a community treatment order is proposed, as well as to the individual's SDM as applicable).

⁶⁶ *M.A. v. Benes*, 1999 Canlii 3807 (ON CA) para. 23.

⁶⁷ Referring to the classical hero Ulysses (Odysseus), who had himself tied to the mast of his ship and his sailors' ears blocked with wax, so that he could hear the song of the sirens without being drawn closer to shore, where he and his sailors would die. See Homer, *The Odyssey*, Book XII, Trans. Samuel Barber, online: The Internet Classics Archive, <http://classics.mit.edu/Homer/odyssey.12.xii.html> (Last accessed, December 10, 2013).

⁶⁸ *HCCA*, note 1, s. 32; *Substitute Decisions Act, 1992*, S.O. 1992, c. 30 s. 50 (*SDA*).

⁶⁹ *SDA*, note 68, s. 50.

⁷⁰ *Starson*, note 5, 759-760.

⁷¹ *HCCA*, note 1, s. 32(5)-(7).

⁷² *HCCA*, note 1, s. 18(1)-(3).

⁷³ *HCCA*, note 1, s. 18(4).

⁷⁴ *HCCA*, note 1, s. 19.

⁷⁵ *HCCA*, note 1, ss. 4(1), 47.1.

⁷⁶ *HCCA*, note 1, s. 2(1); *Evaluators*, O. Reg. 104/96.

⁷⁷ *HCCA*, note 1, s. 46.

⁷⁸ *HCCA*, note 1, ss. 4(1), 55-69.1.

⁷⁹ *SDA*, note 68, s. 45.

⁸⁰ *SDA*, note 68, s. 49(1), see also s. 66(2.1) and s. 67.

⁸¹ *SDA*, note 68, s. 49(2).

⁸² *SDA*, note 68, s. 49(2)-(3).

⁸³ *SDA*, note 68, s.1(1) “assessor”; *Capacity Assessment*, O. Reg. 460/05.

⁸⁴ *SDA*, note 68, s. 78(1).

⁸⁵ *SDA*, note 68, s. 78(2).

⁸⁶ *SDA*, note 68, ss. 50(2), 79.

⁸⁷ Health Care Consent Act, note 3, s. 20; Advocacy Centre for the Elderly, “Tip Sheet # 2 Hierarchy of Substitute Decision Makers (SDMs) in the Health Care Consent Act”, online: Advocacy Centre for the Elderly, http://www.ancelaw.ca/advance_care_planning_-_publications.php (Last accessed November 5, 2013).

⁸⁸ *SDA*, note 68, ss. 55-68.

⁸⁹ *SDA*, note 68, ss. 46-53, 66-68.

⁹⁰ *HCCA*, note 1, ss. 33, 51, 66.

⁹¹ *HCCA*, note 1, ss.20(7)-(8) Definition of Spouse.

⁹² *HCCA*, note 1, s.20(9) Definition of Partner.

⁹³ *HCCA*, note 1, s.20(10) Definition of Relative.

⁹⁴ *HCCA*, note 1, s. 20(6).

⁹⁵ *HCCA*, note 1, ss. 20(2)-(3).

⁹⁶ *HCCA*, note 1, s. 33(6).

⁹⁷ *HCCA*, note 1, s. 33(6)2; D’Arcy Hiltz and Anita Szigeti, *A Guide to Consent & Capacity Law in Ontario*, 2013 Edition (Markham: LexisNexis, 2013) 185-186.

⁹⁸ *HCCA*, note 1, ss. 20(11).

⁹⁹ *HCCA*, note 1, s.20(4), Advocacy Centre for the Elderly, Note 90.

¹⁰⁰ *HCCA*, note 1, ss. 20(5), 41.

¹⁰¹ *HCCA*, note 1, s. 58.

¹⁰² *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3, Sched. A, s. 26(6).

¹⁰³ *HCCA*, note 1, s. 66.

¹⁰⁴ *HCCA*, note 1, s. 21(1).

¹⁰⁵ *HCCA*, note 1, s. 21(2).

¹⁰⁶ *HCCA*, note 1, s. 22.

¹⁰⁷ *M.A. v. Benes*, note 66, para. 23.

¹⁰⁸ *Rasouli*, note 9, paras. 79-88.

¹⁰⁹ *HCCA*, note 1, s. 20(1); *SDA*, Note 68, ss. 46-53, 66-68.

¹¹⁰ *SDA*, note 68, s. 46(7).

¹¹¹ *Re K.M.S.*, 2007 Canlii 29956 (ON CCB), 11.

¹¹² *SDA*, note 68, s. 47(1).

¹¹³ *SDA*, note 68, ss. 47-49.

¹¹⁴ *SDA*, note 68, s. 50.

¹¹⁵ *SDA*, note 56, s. 50.

¹¹⁶ *SDA*, note 68, s. 55.

¹¹⁷ *SDA*, note 68, ss. 58-59.

¹¹⁸ *SDA*, Note 68, ss. 66-67.

¹¹⁹ *M.A. v. Benes*, note 66, paras. 37-39.

¹²⁰ *Rasouli*, Note 9, paras. 97-98.

¹²¹ *Grover v. Grover* (2009), 176 ACWS (3d) 1193, 2009 CarswellOnt 1944 (Ont Sup Ct).

¹²² *HCCA*, note 1, s. 33.

¹²³ *HCCA*, note 1, s. 34.

¹²⁴ *HCCA*, note 1, s. 36.

¹²⁵ *HCCA*, note 1, s. 35.

¹²⁶ *HCCA*, note 1, s. 37(4)-(7).

¹²⁷ *HCCA*, note 1, s. 1(c)(iii).

¹²⁸ *HCCA*, note 1, s. 21.

¹²⁹ *HCCA*, note 1, s. 5.

¹³⁰ Fram, note 6, 288.

¹³¹ Committee Transcripts: Standing Committee on Administration of Justice - December 16, 1991 - Bill 74, Advocacy Act, 1992, and Companion Legislation, at 1700-1710, online: http://www.ontla.on.ca/web/committee-proceedings/committee_transcripts.do?locale=en.

¹³² For example, see *J.C. (Re)*, 2010 Canlii 52741 (ON CCB).

¹³³ Fram, note 6, 251.

¹³⁴ Fram, note 6, 48-49, 144, 253-256.

¹³⁵ *M.A. v. Benes*, note 66, para. 44.

¹³⁶ *HCCA*, note 1, ss. 25-27.

¹³⁷ *HCCA*, note 1, ss. 2(1) and 13.

¹³⁸ *HCCA*, note 1, s. 11(3).

¹³⁹ *Scardoni v. Hawryluck*, (2004) 69 OR (3d) 700, (Ont Sup Ct) (*Scardoni*).

¹⁴⁰ *Scardoni*, note 139, para. 59.

¹⁴¹ *Rasouli*, note 9, at para. 105.

¹⁴² *M.B. (Re)*, 2008 Canlii 3954 (ON CCB) 21-22. see also *K.M.S. (Re)*, 2007 Canlii 29956 (ON CCB) where the CCB held that, even if a statement in a power of attorney was not a wish applicable in the circumstances, it constitute the patient's value and beliefs about the dying process.

¹⁴³ *M.F. (Re)*, 2003 Canlii 14908 (ON CCB) 7-8.

¹⁴⁴ *M.F. (Re)*, note 146, 9.

¹⁴⁵ *M.F. (Re)*, note 146, 9, see also See *I.A. (Re)*, 2004 Canlii 29268 (ON CCB) 15-16.

¹⁴⁶ *S.S. (Re)*, 2012 Canlii 85612 (ON CCB) 14.

¹⁴⁷ *S.S. (Re)*, Note 149, at pp. 13-14, 18; also see *G.S. (Re)* 2012 Canlii 42098 (ON CCB);

¹⁴⁸ *M. (Re)*, 2009 CanLII 33714 (ON CCB) 5-11.

¹⁴⁹ *Barbulov v. Cirone*, 2009 Canlii 15889 (ON SC) paras. 45-48, 61, 95; see also *Friedberg et al. v. Korn*, 2013 ONSC 960.

¹⁵⁰ *Rasouli*, note 9, para. 96.

¹⁵¹ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s. 3.

¹⁵² *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 4.

¹⁵³ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 5.

¹⁵⁴ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 6, “advance directive”.

¹⁵⁵ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 1.

¹⁵⁶ *Representation Agreement Act*, RSBC 1996, c 405.

¹⁵⁷ *Representation Agreement Act*, note 156, ss. 2, 7-8.

¹⁵⁸ *Representation Agreement Act*, note 156, ss. 1 “health care”, 7-8; There are limitations on the treatments to which a representative can consent to, see *Representation Agreement Act*, note 156, s. 9(2).

¹⁵⁹ *Representation Agreement Act*, note 159, ss. 12, 20; We have been advised by a British Columbia lawyer that the requirement for a monitor for financial matters flows from the fact that the test for capacity to appoint a representative is lower than the threshold for capacity to create an enduring power of attorney in British Columbia. This resulted in the extra-protective measures of a monitor for representation agreements addressing financial matters.

¹⁶⁰ *Representation Agreement Act*, note 156, s. 16.

¹⁶¹ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 19.3.

¹⁶² *Representation Agreement Act*, note 156, s. 16.

¹⁶³ *Representation Agreement Act*, note 156, s. 16.

¹⁶⁴ *Representation Agreement Act*, note 156, s. 16(7).

¹⁶⁵ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 19.7.

¹⁶⁶ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 9(1.1) – however, there are some treatments for which consent by advance directive is not possible.

¹⁶⁷ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, ss. 9, 19.7 - 19.8.

¹⁶⁸ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, ss. 19.8(1).

¹⁶⁹ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, ss. 19.8(2).

¹⁷⁰ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, ss. 19.8(3).

¹⁷¹ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 1 “advance directive”.

¹⁷² *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s.19; *Representation Agreement Act*, note 156, s. 16.

¹⁷³ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 16.

¹⁷⁴ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 19; Please note that there are limitations on the treatments to which a temporary substitute decision maker can consent to, see *Health Care Consent Regulation*, BC Reg 20/2000, s. 5.

¹⁷⁵ *Health Care (Consent) and Care Facility (Admission) Act*, note 151, s. 33.4.

¹⁷⁶ *Representation Agreement Act*, note 156, ss. 30-34.

¹⁷⁷ *Personal Directives Act*, RSA 2000, c P-6.

¹⁷⁸ *Personal Directives Act*, note 177, s 1(l).

¹⁷⁹ *Personal Directives Act*, note 177, ss 1(k), 5(1).

¹⁸⁰ *Personal Directives Act*, note 177, s 14(1).

¹⁸¹ *Adult Guardianship and Trustee Act*, SA 2008, c A-4.2.

¹⁸² *Adult Guardianship and Trustee Act*, note 181, ss. 3-10.

¹⁸³ *Adult Guardianship and Trustee Act*, note 181, s. 6.

¹⁸⁴ *Personal Directives Act*, note 177, s 14(2).

¹⁸⁵ *Personal Directives Act*, note 177, s 14(3); Interestingly, agents may also be required to make decisions in accordance with the best interests requirement under the *Alberta Mental Health Act*, RSA 2000, c M-13, s. 28, leaving open the possibility of conflicting decision-making obligations.

¹⁸⁶ *Personal Directives Act*, note 177, s 19(1)(a).

¹⁸⁷ *Personal Directives Act*, note 177, s. 23.

¹⁸⁸ *Personal Directives Act*, note 177, s 19(1)(b).

¹⁸⁹ *Personal Directives Act*, note 177, s 19(2).

¹⁹⁰ *Personal Directives Act*, note 177, s. 14.

¹⁹¹ *Adult Guardianship and Trustee Act*, note 181.

¹⁹² *Adult Guardianship and Trustee Act*, note 181, ss. 87-88.

¹⁹³ *Adult Guardianship and Trustee Act*, note 181, ss. 1 “nearest relative” , 89.

¹⁹⁴ *Adult Guardianship and Trustee Act*, note 181, s. 92

¹⁹⁵ *Adult Guardianship and Trustee Act*, note 181, s. 97; *Personal Directives Act*, note 177, ss. 25-27.

¹⁹⁶ *Personal Directives Act*, note 177, Part 4.1.

¹⁹⁷ *Hospitals Act*, RSNS 1989, c 208 s. 54(1).

¹⁹⁸ *Personal Directives Act* SNS 2008, c 8, s 3(1).

¹⁹⁹ *Personal Directives Act*, note 198, s. 3(1).

²⁰⁰ *Medical Consent Act*, RSNS 1989, c 279, s. 3.

²⁰¹ *Personal Directives Act*, note 198, s. 22(2).

²⁰² *Personal Directives Act*, note 198, s. 15; *Hospitals Act*, RSNS 1989, c 208 s. 54A.

²⁰³ *Personal Directives Act*, note 198, ss. 18(1-2).

²⁰⁴ *Personal Directives Act*, note 198, s. 18(3)(a).

²⁰⁵ *Personal Directives Act*, note 198, s. 18(3)(b).

²⁰⁶ *Personal Directives Act*, note 198, s. 18(3)(c).

²⁰⁷ *Personal Directives Act*, note 198, s. 15; *Hospitals Act*, RSNS 1989, c 208 s. 54A.

²⁰⁸ *Personal Directives Act*, note 198, s 14.

²⁰⁹ *Personal Directives Act*, note 198, s 14(2).

²¹⁰ *Personal Directives Act*, note 198, s. 15(4)(a).

²¹¹ *Personal Directives Act*, note 198, s. 15(4)(b).

²¹² *Hospitals Act*, note 197, s. 54(2).

²¹³ *Personal Directives Act*, note 198, ss. 29-31.

²¹⁴ *Hospitals Act*, note 197, ss. 54D, 58(2).

²¹⁵ *Involuntary Psychiatric Treatment Act*, SNS 2005, c 42, s. 65.

²¹⁶ *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 1997, c H-0.001, ss. 2(1)(c), Part II.

²¹⁷ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 5(1).

²¹⁸ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 5(2).

- ²¹⁹ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 12.
- ²²⁰ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 12.
- ²²¹ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s 5(1).
- ²²² *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 2(1)(d).
- ²²³ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 5(1).
- ²²⁴ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, ss. 12, 16(3).
- ²²⁵ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 16.
- ²²⁶ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 15(1)(a-h).
- ²²⁷ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 16(3).
- ²²⁸ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 16(4).
- ²²⁹ *Health Care Directives and Substitute Health Care Decision Makers Act*, note 216, s. 20.
- ²³⁰ *Mental Capacity Act 2005* (UK), 2005, c 9, ss. 42-43; *Mental Capacity Act 2005: Code of Practice*, (London: Department for Constitutional Affairs, 2007) online: Imperial College London, <http://www3.imperial.ac.uk/pls/portallive/docs/1/51771696.PDF> (Last accessed October 21, 2013) [Code of Practice].
- ²³¹ *Mental Capacity Act*, note 230, ss. 24-26.
- ²³² *Mental Capacity Act*, note 230, s 9(1).
- ²³³ *Mental Capacity Act*, note 230, s 19.
- ²³⁴ *Mental Capacity Act*, note 230, s 19(1).
- ²³⁵ *Mental Capacity Act*, note 230, ss. 11, 20.
- ²³⁶ *Mental Capacity Act*, note 230, s 4.
- ²³⁷ *Mental Capacity Act*, note 230, s 26(1).
- ²³⁸ *Mental Capacity Act*, note 230, s 25.
- ²³⁹ *Mental Capacity Act*, note 230, s 25(5).
- ²⁴⁰ *Mental Capacity Act*, note 230, s. 4(6).
- ²⁴¹ *Mental Capacity Act*, note 230, s. 9(4).

²⁴² *Mental Capacity Act*, note 230, s 11(1).

²⁴³ *Mental Capacity Act*, note 230, s 11(7).

²⁴⁴ *Mental Capacity Act*, note 230, s 11(8)(a).

²⁴⁵ *Mental Capacity Act 2005: Code of Practice*, note 230, at 171.

²⁴⁶ *Mental Capacity Act 2005: Code of Practice*, note 230, at 176.

²⁴⁷ *Mental Capacity Act 2005: Code of Practice*, note 230, at 119-120.

²⁴⁸ *Mental Capacity Act 2005: Code of Practice*, note 230, at 152.

²⁴⁹ *Mental Capacity Act*, note 230, s 4.

²⁵⁰ *Mental Capacity Act*, note 230, s 4(6).

²⁵¹ *Mental Capacity Act 2005: Code of Practice*, note 230, at 69-70.

²⁵² *Mental Capacity Act*, note 230, ss. 37, 40.

²⁵³ *Mental Capacity Act*, note 230, s. 45-49.

²⁵⁴ *Code of Practice*, note 230, 137.

²⁵⁵ *Code of Practice*, note 230, 177.

²⁵⁶ British Medical Association, "Consent Too kit", 11, online: British Medical Association, <http://bma.org.uk/practical-support-at-work/ethics/consent-tool-kit> (Last accessed November 5, 2013).

²⁵⁷ *Aintree University Hospitals NHS Foundation Trust v. James*, [2013] UKSC 67, paras. 19, 23.

²⁵⁸ *Guardianship and Administration Act 2000* (Qld), s. 64; see also Queensland Health, *Guide to Informed Decision-making in Healthcare* (Herston Queensland: Centre for Healthcare Improvement, 2012) Part 2.3, online: Queensland Government, <http://www.health.qld.gov.au/consent/documents/ic-guide.pdf> (Last accessed December 5, 2013).

²⁵⁹ *Powers of Attorney Act 1998* (Qld), s. 5(4).s 35.

²⁶⁰ *Powers of Attorney Act 1998* (Qld), note 260, s. 36(2).

²⁶¹ *Powers of Attorney Act 1998* (Qld), note 260, ss. 32-33.

²⁶² *Powers of Attorney Act 1998* (Qld), Schedule 1, ss.7, 12.

²⁶³ Queensland Health, note 258, 24.

²⁶⁴ *Powers of Attorney Act 1998* (Qld), note 260, s. 36.

²⁶⁵ *Guardianship and Administration Act 2000* (Qld), s. 66.

²⁶⁶ Queensland Health, note 258, 24.

²⁶⁷ *Powers of Attorney Act 1998* (Qld), note 260, s. 101.

²⁶⁸ Queensland Health, note 258, 24.

²⁶⁹ *Powers of Attorney Act 1998* (Qld), note 260, s. 76.

²⁷⁰ *Powers of Attorney Act 1998* (Qld), Schedule 1, Part 2.

²⁷¹ *Powers of Attorney Act 1998* (Qld), note 260, ss. 62-63.

²⁷² *Queensland Civil and Administrative Tribunal Act 2009* (Qld); *Guardianship and Administration Act 2000* (Qld), Chapters. 5-7.

²⁷³ Robert S Olick, “*Defining Features of Advance Directives in Law and Clinical Practice.* (212) Chest 141(1), 232.

²⁷⁴ Stuart Zimring, “Health Care Decision-Making Capacity: A Legal Perspective for Long-Term Care Providers” (June 2006), *Journal of the American Medical Directors Association*, Volume 7, Issue 5, 323.

²⁷⁵ Olick, note 273, 232.

²⁷⁶ See Oregon POLST Task Force, “Guidance for Oregon’s Health Care Professionals”, May 2012, online: Oregon POLST Task Force, www.oregonpolst.org/wp-content/uploads/2012/11/GuidebookMay2012final.pdf (Last accessed November 28, 2013).

²⁷⁷ Oregon Revised Statutes, Title 13, Ch. 127.625 (ORS); see also Hawaii Revised Statutes, Div. 1, Title 19, Ch.327-E7 (HRS) and Texas Health and Safety Code, Title 2, Subtitle H, Ch. 166, ss.166.045-166.046 (THSC).

²⁷⁸ Zimring, note 274, 323.

²⁷⁹ University of Hawaii Elder Law Program, “Health Care Decision Making” online: University of Hawaii, <http://www.hawaii.edu/uhelp/healthcare.htm> (Last accessed November 4, 2013).

²⁸⁰ Hawaii Administrative Rules, Title 16, Ch.85-25.

²⁸¹ HRS, note 277, Ch.327E.

²⁸² HRS, note 277, Ch.327K.

²⁸³ HRS, note 277, Ch.327E, note: HRS, Title 30, s.551D-2.5, addressing Guardians and Trustees, varies slightly, stating that “a competent person who has attained the age of majority may execute a durable power of attorney authorizing an agent to make any lawful health care decisions pursuant to chapter 327E.”

²⁸⁴ HRS, note 277, s.327E-3(a)-(b).

²⁸⁵ HRS, note 277,s.327E-3(g).

²⁸⁶ HRS, note 277, s.327E-2.

²⁸⁷ HRS, note 277, s. 327E-3(g).

²⁸⁸ HRS, note 277, s.327E-7(d).

²⁸⁹ HRS, note 277, s.327E-5(a).

²⁹⁰ HRS, note 277, s.327E-5(f).

²⁹¹ HRS, note 277, s.327E-2.

²⁹² HRS, note 277, s.327E-2.

²⁹³ HRS, note 277, s.327E-5(b).

²⁹⁴ HRS, note 277, S. 327E-5(g).

²⁹⁵ HRS, note 277, s.327E-5(g).

²⁹⁶ HRS, note 277, s.327E-14.

²⁹⁷ HRS, note 277, s.327K-1.

²⁹⁸ HRS, note 277,s.327K-2(a).

²⁹⁹ HRS, note 277,s.327K-2(d).

³⁰⁰ HRS, note 277,s.327K-2(a).

³⁰¹ HRS, note 277,s.327K-2(c).

³⁰² HRS, note 277, s.327K-2(a).

³⁰³ ORS, note 277, Ch. 127.507.

³⁰⁴ ORS, note 277, Ch. 677.097.

³⁰⁵ ORS, note 277, Ch. 127.505 - 127.660.

³⁰⁶ ORS, note 277,Ch. 127.505(12).

³⁰⁷ ORS, note 277,Ch. 127.535(4).

³⁰⁸ ORS, note 277, Ch. 127.535(4).

³⁰⁹ ORS, note 277, Ch.127.565.

³¹⁰ ORS, note 277, Ch.127.531.

³¹¹ ORS, note 277, Ch.127.760(3)(c).

³¹² ORS, note 277, Ch.127.555(3).

³¹³ ORS, note 277, Ch.127.565.

³¹⁴ ORS, note 277, Ch.127.635.

³¹⁵ ORS, note 277, Ch. 127.760.

³¹⁶ ORS, note 277, Ch. 127.635(3).

³¹⁷ ORS, note 277, Ch. 127.550.

³¹⁸ ORS, note 277, Ch. 127.550.

³¹⁹ ORS, note 277, Ch.127.663-127.684.

³²⁰ Oregon Administrative Rules 847-35-0030(6) (OAR); See also “Guidance for Oregon’s Health Care Professionals”, note 281.

³²¹ OAR, note 320, 847-35-0030(6); See also “Guidance for Oregon’s Health Care Professionals”, note 281, 1.

³²² Oregon Administrative Rules, note 320, 8.

³²³ THSC, note 277, ss. 74.104-74.105; see also Texas Medical Association, “Informed Consent” (February 2012) online: Texas Medical Association, <http://www.texmed.org/Template.aspx?id=6049> (Last accessed November 4, 2013).

³²⁴ THSC, note 277, s.166.152(a) [THSC].

³²⁵ THSC, note 277, s.166.158(a).

³²⁶ THSC, note 277, s.166.152(e).

³²⁷ THSC, note 277, s.166.032.

³²⁸ THSC, note 277, s.166.038(b).

³²⁹ THSC, note 277, s.166.038(c).

³³⁰ THSC, note 277, Ch. 166, Subchapter C.

³³¹ THSC, note 277, s.166.081.

³³² THSC, note 277, s.166.090(a).

³³³ THSC, note 277, s.166.082.

³³⁴ THSC, note 277, s.166.087.

³³⁵ THSC, note 277, s.166.039(c), 166.088(c).

³³⁶ THSC, note 277, s.166.039(e).

³³⁷ THSC, note 277, s.166.152(e).

³³⁸ THSC, note 277, s.166.039(b).

³³⁹ THSC, note 277, s.166.039(e).

³⁴⁰ THSC, note 277, s.166.039.

³⁴¹ THSC, note 277, ss. 166.039(g), 166.088(g).

³⁴² THSC, note 277, ss. 166.046.

³⁴³ HRS, note 277, Ch..327E-7(d).

³⁴⁴ Dunbrack, note 11, 19, 28.

³⁴⁵ Dunbrack, note 11, 19-20.

³⁴⁶ For example, statement that “choice, autonomy and self-determination” is a “Charter right” is broadly correct, but does not recognize some of the limitations on this right. For example, the Charter right to patient autonomy, in the authors’ opinion, does not require that uninformed wishes must be complied with by health practitioners.

³⁴⁷ Fram, note 6, 251.

³⁴⁸ *HCCA*, note 1, s. 29.

³⁴⁹ Our review the below documents was not exhaustive, but was focussed on the themes identified in this paper. The fact that we have not commented on a particular passage of a document, should not be interpreted as an endorsement of that passage.

³⁵⁰ *Consent Policy*, note 64, at 6.

³⁵¹ College of Physicians and Surgeons of Ontario, *Decision-making for the End of Life, Policy Number: #1-06*, (February 2006), 8, online : College of Physicians and Surgeons of Ontario, <http://cpso.on.ca/policies-publications/policy/decision-making-for-the-end-of-life>

(Last accessed: October 4, 2013) (*End of Life Policy*).

³⁵² ACE has prepared a broader commentary on the Consent and End of Life Policies, which can be accessed on the CPSO website through the below links:

<http://policyconsult.cpsso.on.ca/wp-content/uploads/2013/11/ACE-Consultation-Feedback-End-of-Life-Nov-22-2013.pdf>; <http://policyconsult.cpsso.on.ca/wp-content/uploads/2013/11/ACE-Consultation-Feedback-Consent-Nov-22-2013.pdf> (Last accessed January 2, 2014).

³⁵³ *End of Life Policy*, note 351, 2.

³⁵⁴ *End of Life Policy*, note 351, 3.

³⁵⁵ *End of Life Policy*, note 351, 5.

³⁵⁶ *End of Life Policy*, note 351, 4-5.

³⁵⁷ Canadian Medical Protective Association, “End-of-life care – Support, comfort, and challenging decisions” (Ottawa: Canadian Medical Protective Association, 2011) online: CMPA, https://oplfrpd5.cmpa-acpm.ca/safety/-/asset_publisher/N6oEDMrzRbCC/content/end-of-life-care-%E2%80%94-support-comfort-and-challenging-decisions;jsessionid=A9B6D8C0BFE1B4901A9F8C3E73284149

(Last accessed: October 21, 2013) (*End-of-life-care*).

³⁵⁸ Kenneth G. Evans, *Consent: A Guide for Physicians, Fourth Edition* (Ottawa: Canadian Medical Protective Association, 2006) online: CMPA, https://oplfrpd5.cmpa-acpm.ca/documents/10179/24897/com_consent-e.pdf (Last accessed October 21, 2013).

³⁵⁹ Canadian Medical Protective Association, *Medico-Legal Handbook for Physicians in Canada, Seventh Edition* (Ottawa: Canadian Medical Protective Association, 2010) 24-29, online: CMPA, https://oplfrpd5.cmpa-acpm.ca/documents/10179/24891/com_medico_legal_handbook-e.pdf/a603321b-0721-4574-b216-4fe5b5701c8e (Last accessed October 21, 2013) (*Medico-Legal Handbook*).

³⁶⁰ *End-of-life-care*, note 357, 3.

³⁶¹ *Medico-Legal Handbook*, note 359, 28; *End-of-life-care*, note 277, 1.

³⁶² *Medico-Legal Handbook*, note 359, 28.

³⁶³ *Medico-Legal Handbook*, note 359, 25.

³⁶⁴ Evans, note 358, 6.

³⁶⁵ Canadian Medical Association, Canadian Nurses Association, Canadian Healthcare Association, and Catholic Health Association, “Joint Statement on Resuscitative Interventions” *Can Med Assoc J.* Dec 1, 1995; 153(11) 1652A–1652F. (Ottawa: Canadian Medical Association, 1995) online: NCBI, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1488016/pdf/cmaj00083-0099.pdf> (Last Accessed October 21, 2013) (Joint Statement).

- ³⁶⁶ Canadian Medical Association, *Advance Directives for Resuscitation and other Life-Saving or Sustaining Measures*. (Ottawa, Canadian Medical Association, 1992) online: CMA, <http://policybase.cma.ca/dbtw-wpd/PolicyPDF/PD92-02.pdf> (Last Accessed October 21, 2013) (*Advance Directives for Resuscitation*).
- ³⁶⁷ Joint Statement, note 365, 1652A–1652F.
- ³⁶⁸ *Advance Directives for Resuscitation and other Life-Saving or Sustaining Measures*, note 366, 1-2.
- ³⁶⁹ Joint Statement, note 365, 1652A–1652.
- ³⁷⁰ Canadian Medical Association, online: <http://www.cma.ca/advance-directives-resuscitative-intervention> (Last Accessed October 21, 2013).
- ³⁷¹ College of Nurses of Ontario, *Consent* (Toronto: College of Nurses of Ontario, 2009) online, CNO, http://www.cno.org/Global/docs/policy/41020_consent.pdf (Last accessed October 21, 2013).
- ³⁷² College of Nurses of Ontario, *Guiding Decisions About End-of-Life Care, 2009* (Toronto: College of Nurses of Ontario, 2009) online, CNO, http://www.cno.org/Global/docs/prac/43001_Resuscitation.pdf (Last accessed October 21, 2013).
- ³⁷³ Ian Anderson Continuing Education Program in End-of Life Care, University of Toronto, “Overview” online: <http://www.cme.utoronto.ca/endoflife/Overview.htm> (Last accessed November 15, 2013).
- ³⁷⁴ Ian Anderson Continuing Education Program in End-of Life Care, University of Toronto, “Module 4 End-of-Life Decision-Making” online: <http://www.cme.utoronto.ca/endoflife/Modules/End-of-Life%20Decision-Making%20Module.pdf> (Last accessed November 15, 2013) (Ian Anderson Module).
- ³⁷⁵ Ian Anderson Module, note 374, 45.
- ³⁷⁶ Ian Anderson Module, note 374, 27-28.
- ³⁷⁷ Ian Anderson Module, note 374, 22.
- ³⁷⁸ Ian Anderson Module, note 374, 45.
- ³⁷⁹ Ian Anderson Module, note 374, 6,7.
- ³⁸⁰ Ian Anderson Continuing Education program in End-of-Life Care website: <http://www.cme.utoronto.ca/endoflife/Modules.htm> (Last accessed January 2, 2013).
- ³⁸¹ Ian Anderson Module, note 374, 22.
- ³⁸² EFPPEC Website: <http://www.afmc.ca/efppec/pages/main.html> (Last accessed January 5, 2014).

³⁸³ EFPPEC, note 14.

³⁸⁴ We should also note that ACE does not endorse these materials.

³⁸⁵ EFPPEC, note 14, 7.

³⁸⁶ EFPPEC, note 14, 13.

³⁸⁷ For example, see EFPPEC, note 14, 3, 7.

³⁸⁸ For example, see EFPPEC, note 14, 27.

³⁸⁹ For example, see EFPPEC, note 14, 54.

³⁹⁰ Our review the below documents was not exhaustive, but was focussed on the themes identified in this paper. The fact that we have not commented on a particular passage of a document, should not be interpreted as an endorsement of that passage.

³⁹¹ Interrai, “Long-Term Care Facilities” online, Interrai: <http://www.interrai.org/long-term-care-facilities.html> (Last accessed November 5, 2013).

³⁹² Ontario Ministry of Health and Long-Term Care, Press Release: “Improving Care For Residents In Long-Term Care Homes” (May 5, 2009) online, Ontario Government: <http://news.ontario.ca/mohltc/en/2009/05/improving-care-for-residents-in-long-term-care-homes.html> (Last accessed November 5, 2013).

³⁹³ Interrai and Canadian Institute of Health Information, *Resident Assessment Instrument (RAI)*

RAI-MDS 2.0 User’s Manual, Canadian Version, (Ottawa: Canadian Institute of Health Information, February 2012) (*RAI-MDS 2.0 User’s Manual*).

³⁹⁴ *RAI-MDS 2.0 User’s Manual*, note 393, 247.

³⁹⁵ *RAI-MDS 2.0 User’s Manual*, note 393, 69.

³⁹⁶ Canadian Hospice Palliative Care Association, online: <http://www.advancecareplanning.ca/> (Last accessed, October 30, 2013).

³⁹⁷ Canadian Hospital Palliative care Association, *Advance Care Planning Workbook Ontario Edition*, (Ottawa: CHPCA) online: CHPCA, http://www.advancecareplanning.ca/media/73433/acp_ontario_workbook_final-rev2013-web.pdf (Last accessed, October 30, 2013).

³⁹⁸ CHPCA, note 397, 5.

³⁹⁹ CHPCA, note 397, 13-14.

⁴⁰⁰ CHPCA, note 397, 14.

⁴⁰¹ Ian Anderson Module, note 374, 28.

⁴⁰² “This Year Give Something Different” online: Canadian Hospice Palliative Care Association, http://advancecareplanning.ca/media/101944/acp_holiday_infographics_2013_-_give_something_different_web.pdf (Last accessed December 17, 2013).

⁴⁰³ Cancer Care Ontario, “Advance Care Planning Quality Improvement Toolkit” (October 2013) online: Cancer Care Ontario, <https://www.cancercare.on.ca/pacs/primcare/qitoolkit/> (Last accessed November 4, 2013).

⁴⁰⁴ “Advance Care Planning Quality Improvement Toolkit”, note 403.

⁴⁰⁵ “Advance Care Planning Quality Improvement Toolkit”, note 403, 19-28.

⁴⁰⁶ “Advance Care Planning Quality Improvement Toolkit”, note 403, 18, 24.

⁴⁰⁷ “Advance Care Planning Quality Improvement Toolkit”, note 403, 18, 24;

American Family Physician, “Sample Advance Directive Form” online: American Family Physician, <http://www.aafp.org/afp/1999/0201/p617.html> (Last accessed November 4, 2013).

⁴⁰⁸ “Advance Care Planning Quality Improvement Toolkit”, note 403, 24; Respecting Choices Gunderson Health System, online: <http://www.gundersenhealth.org/respecting-choices> (Last accessed January 3, 2014).

⁴⁰⁹ “Advance Care Planning Quality Improvement Toolkit”, note 403, 18.

⁴¹⁰ “Advance Care Planning Quality Improvement Toolkit”, note 403, 6.

⁴¹¹ Cancer Care Ontario, “Advance Care Planning with Cancer Patients” (April 2012) 15 (22 in pdf), online: Cancer Care Ontario, <https://www.cancercare.on.ca/common/pages/UserFile.aspx?serverId=6&path=/File%20Database/CCO%20Files/PEBC/pebc19-1f.pdf> (Last accessed November 4, 2013).

⁴¹² See “Advance Care Planning with Cancer Patients”, note 411, 4 (5 in pdf).

⁴¹³ Robert w. Sibbald, Paula Chidwick, Mark Handelman and Andrew B. Cooper, “Checklist to Meet Ethical and Legal Obligations to Critically Ill Patients at End of Life” *Healthcare Quarterly*, Vol. 14, No. 4, 2011, 60-66.

⁴¹⁴ Checklist for meeting Ethical and Legal Obligations (ChELO), application by Healthcare Consent Quality Collaborative, online: <http://consentqi.ca/projects/chelo/>

(Last accessed January 6, 2014) (ChELO Application).

⁴¹⁵ Sibbald, note 413, at p. 64; see also ChELO Application, Note 414.

⁴¹⁶ ChELO Application, note 414.

⁴¹⁷ Fraser Health, “Medical Orders for Scope of Treatment (MOST) and Advance Care Planning (ACP), June 13, 2013, online: Fraser Health, <http://www.fraserhealth.ca/media/Medical%20Orders%20for%20Scope%20of%20Treatment%20>

[MOST\)%20and%20Advance%20Care%20Planning%20\(ACP\).pdf](#) (Last accessed ,October 31, 2013).

⁴¹⁸ Fraser Health, note 417, 1, 3.

⁴¹⁹ Ministry of Health and Long-Term Care, Training Bulletin, Issue Number 108 – version 1.0 Do Not Resuscitate (DNR) Standard, November 29, 2007, Ministry of Health and Long-Term Care, 3, online: Ministry of Health and Long-Term Care, http://www.ambulance-transition.com/pdf_documents/training_bulletin_108_v1_dnr_standard.pdf (Last accessed January 3, 2014).

⁴²⁰ Ontario Ministry of Citizenship, *A Guide to Advance Care Planning* (Toronto: Ontario Seniors' Secretariat) online: Ontario Seniors' Secretariat, <http://www.seniors.gov.on.ca/en/advancedcare/docs/AdvancedCare.Guide.pdf> (Last accessed October 31, 2013).

⁴²¹ Ontario Ministry of Citizenship, note 420, 14, 28.

⁴²² INTERACT, "Interventions to Reduce Acute Care Transfers website", online: INTERACT, <http://interact2.net/about.html> (Last accessed November 1, 2013).

⁴²³ "©2011 Florida Atlantic University, all rights reserved. This document is available for clinical use, but may not be resold or incorporated in software without permission of Florida Atlantic University".

⁴²⁴ "Advance Care Planning Tracking Form, *INTERACT Version 3.0 Tools*, 2, online: INTERACT <http://interact2.net/docs/INTERACT%20Version%203.0%20Tools/Advance%20Care%20Planning%20Tools/INTERACT%20Advance%20Care%20Planning%20Tracking%20Form%20Dec%2029%202012.pdf> (Last accessed November 1, 2013) (*INTERACT Version 3.0 Tools*).

⁴²⁵ "Advance Care Planning Communication Guide", *INTERACT Version 3.0 Tools*, 1, online: INTERACT, http://interact2.net/docs/INTERACT%20Version%203.0%20Tools/Advance%20Care%20Planning%20Tools/INTERACT%20ACP_Communication_Guide%20Jan%2019%202013.pdf (Last accessed January 5, 2014).

⁴²⁶ D.W. Molloy, Rosalie Russo, Angela Stiller, and M.J. O'Donnell, "How to Implement the "Let me Decide" Advance Health and Personal Care Directive Program" (September 2000) Vol 7 No. 9 JCOM 41, 41-47, online: http://www.turner-white.com/pdf/jcom_sep00_how.pdf (Last accessed December 30, 2013).

⁴²⁷ Dr. Michael Gordon, "WHO CAN YOU TRUST WITH YOUR MOST IMPORTANT END-OF-LIFE DECISIONS: LESSONS FROM THE ONTARIO COURT OF APPEAL?" Whaley Estate Litigation Newsletter Vol.3 No. 9 December 2013, online: <http://archive.constantcontact.com/fs189/1105045552020/archive/1115958674352.html> (Last accessed December 30, 2013).

⁴²⁸ Molloy et al, note 426, 43.

⁴²⁹ Molloy et al, note 426, 43.

⁴³⁰ *Schedule of Benefits for Physician Services under the Health Insurance Act*, effective October 1, 2013, 9, online: Ontario Ministry of Health and Long-Term Care,

<http://www.health.gov.on.ca/english/providers/program/ohip/sob/physsserv/genpre.pdf> (Last accessed December 31, 2013).

⁴³¹ Judith Wahl, "Health Care Consent and Advance Care Planning: Fairly Good Law, Good Intent, but Not Always Good in Practice" (2013) Advocacy Centre for the Elderly, 1-2.

⁴³² *M.A. v. Benes*, note 64, para. 23.

⁴³³ *Excellent Care for All Act*, 2010, S.O. 2010, c. 14.

⁴³⁴ Accreditation Canada, *Senior Population Standards* (April 25, 2013) 15.

⁴³⁵ *Capacity Assessment*, O. Reg. 460/05.

⁴³⁶ *HCCA*, note 1, s. 2.

⁴³⁷ *HCCA*, note 1, s. 21(2).

⁴³⁸ *HCCA*, note 1, s. 4.

⁴³⁹ *HCCA*, note 1, s. 25.

⁴⁴⁰ *HCCA*, note 1, s. 2.

⁴⁴¹ *Evaluators*, O. Reg. 104/96.

⁴⁴² *Regulated Health Professions Act, 1991*, S.O. 1991, c. 18, Schedule 1.

⁴⁴³ *HCCA*, note 1, s. 2.

⁴⁴⁴ *SDA*, note 68, s. 45.

⁴⁴⁵ *HCCA*, note 1, s. 2.

⁴⁴⁶ *HCCA*, note 1, s. 21(1).

⁴⁴⁷ *HCCA*, note 1, s. 2.