



LAW COMMISSION OF ONTARIO
COMMISSION DU DROIT DE L'ONTARIO

HEALTH CARE CONSENT, ADVANCE CARE PLANNING, AND GOALS OF CARE PRACTICE TOOLS: THE CHALLENGE TO GET IT RIGHT

Improving the Last Stages of Life

December 2016

Commissioned by the Law Commission of Ontario

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The LCO commissioned this paper to provide background research for its "Improving the Last Stages of Life" project. The views expressed in this paper do not necessarily reflect the views of the LCO.

EXECUTIVE SUMMARY

The demand for pre-planning by patients about future health care decisions has dramatically increased, particularly for end-of-life care. Despite any pre-planning that is done, in Canada, it is firmly established that the decision-making process requires health practitioners to obtain informed consent before providing treatment. In Ontario, this is a requirement of the Health Care Consent Act¹ (HCCA), which provides that consent be obtained from capable patients and otherwise, from their substitute decision-makers (SDMs).

There is considerable variability between provinces in the components of the pre-planning process, which may include advance care planning (ACP) conversations, and/or goals of care (GOC) discussions, as well as potential documentation of the outcomes of either or both. In Ontario, pre-planning is limited to the expression of wishes, values and beliefs as they relate to future health treatments and care. On the other hand, consent requires any health care decision (as distinguished from wishes) to be given only after the patient received information about their health condition and treatment options. This requirement helps to protect the patient's rights and ensure that health care decision-making, whether by a patient or the incapable patient's SDM, is always done in context and with full information.

Across health settings, policies, practices and associated forms have been developed to encourage or require patients (or their SDM(s)) to articulate their preferences for future health care. This push for pre-planning has extended across the many settings where health services are provided. Unfortunately, it is clear that not all elements of this pre-planning comply with applicable health legislation, nor reflect the limits prescribed by law.

While a diversity of health care consent (HCC), ACP and GOC policies, toolkits and forms have been developed in Ontario, there is limited research evaluating their use, or whether these practice tools appropriately reflect the current legal landscape. The focus of this research paper is to gain a better understanding of current HCC, ACP and GOC practice tools used across the province, to explore how these are implemented, and to determine whether they support decision-making for end-of-life care in the appropriate legal framework.

The Background section of this research paper reviews the legal framework within Ontario, positioning ACP, GOC and HCC as part of the person-centred decision making process. It also clarifies the linkages between informed consent, ACP and GOC, highlighting the connections to

¹ *Health Care Consent Act, 1996*, S.O. 1996, c. 2 Sched. A (HCCA) s.10(1).

the HCCA. Finally, this section summarizes the types of tools that are available for HCC, ACP and GOC.

The methods section describes the multiple methods of data collection used to inform this research paper. To begin, a variety of practice tools were reviewed, and were compared and evaluated against the Ontario legal framework. To complement the practice tool evaluation, a combination of targeted interviews, focus groups, and a literature review of case law and academic articles were also completed.

The Findings section outlines the results of the tool assessment as well as the interviews and focus groups. A total of 100 tools were reviewed and assessed using the screening survey. Of these, 43 had a focus on HCC, 43 had a focus on ACP, and 9 had a focus on GOC; as well, 18 tools had overlapping foci on two or more areas. An additional 23 tools were identified with an “other” focus, which included topics such as decision-making, CPR, and SDMs. Overall, there were numerous issues noted across tools, in particular, very few contextualized these processes appropriately, typically omitting the connection to the law, and often lacking key definitions.

Various themes emerged from the interviews and the focus groups. To begin, knowledge and understanding of HCC, ACP and GOC was variable among stakeholder groups, relating to a lack of available information, and difficulty accessing information. There was a lack of awareness among the general public around these concepts, and how they are related. There was also acknowledgement that many turn to other jurisdictions to meet their information needs in the absence of Ontario-specific material. Language, the role of health literacy, and culture all emerged as factors that restrict access to materials, impacting knowledge and understanding of these concepts. Health practitioners were perceived as having a basic knowledge of HCC, ACP and GOC, but not always recognizing the distinction between these concepts. Importantly, knowledge of these concepts did not always translate into practice, and there was an underlying preoccupation with treatment-centered discussions. Stakeholders consistently identified health practitioner discomfort with discussing HCC, ACP, and GOC, and suggested various contributing factors. Finally, stakeholders identified a lack of enforcement mechanisms under the HCCA.

The discussion section focuses on analysing some of the current challenges and barriers that lead to the misperceptions, and embedded misunderstandings of HCC, ACP and GOC:

- The connections between HCC, ACP and GOC are often missed. Unless this interconnection is understood, it is unlikely that existing tools will be used appropriately; or that flaws in existing tools will be identified or understood.

This has the potential to impact the appropriate use and development of practice tools.

- There is limited education on HCC, ACP and GOC, with noticeable gaps in communications skills training, and an absence of these three processes as part of existing curriculum content.
- There is no one voice of “authority” and no one “regulatory body”, to which all health practitioners and all health care organizations account, or to which they turn as a resource. Although adherence to the HCC and ACP legal framework are acknowledged as being a central element to “person-centred care”, there are also pressures in the health system to deliver health care faster, cheaper, and more efficiently. How that is defined may limit, or in some circumstances prevent, the ability of health practitioners to adhere to the best HCC and ACP processes.
- Health practitioners receive varied messages from the many authorities with whom they interact. Further, messaging within a given authority is sometimes inconsistent. Despite the excellent work of many health sector organizations, health practitioners and others on the frontline occasionally receive mixed messages about what is a good practice in respect to HCC, ACP and GOC.
- There are misunderstandings about the requirement for capacity to make treatment decisions. Some health practitioners do not understand that it is their role to determine capacity nor that it is a legal requirement of the HCCA. Others have expressed that they are not comfortable with completing capacity assessments.
- Team members do not always provide sufficient information to get an effective informed consent. Delegating informed consent is only appropriate if the person to whom the task is delegated actually gets a legal, informed consent.
- There is a reliance on consents or ACP wishes obtained elsewhere, which may not contain accurate or essential information, resulting in the misuse of forms.
- Team members and non-clinical staff are engaging in ACP conversations, which may limit the amount of information that can be shared with the patient. One risk of this approach is that the concept of making wishes is presented in isolation, without connecting it to the spectrum of ACP, GOC and informed consent.
- Practice tools use incorrect language, or fail to clarify the distinction between HCC, ACP and GOC, leading to the inappropriate use of these tools as consent, or to limit treatment options.

- Accreditation standards include references to terms that are not defined under the Health Care Consent Act. It is unclear how a health care organization would seek to comply with standards with these references.
- There are only limited penalties for non-compliance and good faith exemptions within the case law.
- There is limited consideration for legal issues, and legal involvement is rare as part of the practice tool development or review process. Many of the stakeholders interviewed confirmed that materials had not undergone any legal review.
- The published peer reviewed materials do not always reflect the elements of the Ontario law and the legal issues are not considered in the research.

The conclusion and recommendations section summarizes that while informed consent is fundamental to patient-centred care, the various issues and challenges identified in this research paper suggest that it is often neglected. Efforts that are meant to empower patients place little to no emphasis on HCC and embed a model of ACP that is not aligned with Ontario legislation. As a result, patients' rights to make informed decisions about their own care may be compromised.

From a legislative perspective, the HCCA strikes an important balance. In Ontario, the requirement for informed consent prior to treatment being offered not only ensures that patient autonomy is respected, but it also ensures that treatment decisions are contextualized. The fact that ACP and HCC are interconnected in Ontario is also beneficial, because this enables important preparation for the SDM to ensure that any decisions they make on behalf of the incapable patient are also contextualized as well as maintain that patient's preferences.

The HCCA is sound, and does not warrant any major changes. That said, based on what was identified in this research paper, the HCCA has not been adequately embedded into the health system, and the issues are primarily linked to implementation, and enforcement.

The conclusion of this research paper is that a set of standardized practice tools would not be possible because tool development is so widespread, it has become an "industry". Furthermore, there is no one set of "perfect" practice tools. There are different types of health practices and services so everyone sees need for variants on a tool as no one set of products would meet all needs.

It is possible to list a set of types of practice tools that are commonly requested by health practitioners, by patients, patients' families and future SDMs, and by other players in the health system as broadly defined.

The authors offer the following recommendations, where they believe the legal framework for health decision-making could be better integrated into the health system:

1. To improve practice tools, the terminology and language of the HCCA should be used, and nomenclature derived from other jurisdictions should be eliminated.
2. All stakeholders (including health practitioners, health care organization leadership responsible for professional practice, policy-makers, as well as patients, SDMs and the general public) must receive education on HCC, GOC and ACP (as described in Ontario law) and the interrelationships between these three concepts. Training for health practitioners must include communication skills so that they can confidently engage patients and SDMs in ACP conversations and GOC discussions, and effectively obtain informed consent. Education for patients and SDMs should focus on the same fundamental aspects as outlined for health practitioners. Patients and SDMs also need information on their rights and roles in these processes so that they can effectively engage with health practitioners in consent, GOC and ACP discussions.
3. Health leadership funding for HCC and ACP initiatives must require legal accuracy as a condition of funding. Any body regulating or providing oversight of health services providers must also require legal accuracy of any type of practice tool and include review or inspection of such practice tools as part of the oversight or regulatory process.
4. The legal framework for HCC, GOC and ACP must be reinforced system-wide at all levels, including with MOHLTC, LHINS, HQO, health regulatory Colleges, professional and health sector associations, hospital boards and senior leadership, long-term care home operators, senior leadership in other health care organizations, the Patient Ombudsman, patient advocacy groups, Accreditation Canada, other accreditation bodies and others. All of these stakeholders are responsible for promoting compliance to effect necessary changes. Health sector leadership organizations could play a major leadership role in promoting HCCA compliance as fundamental to all health initiatives.

At the end of this section, the authors offer a table of suggested content areas to consider for inclusion when developing practice tools.

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I. INTRODUCTION

The demand for pre-planning by patients about future health care decisions, particularly for end-of-life care, has dramatically increased. In Canada, it is firmly established that part of the decision-making process requires health practitioners to obtain informed consent before providing any treatment. In Ontario, this is a requirement of the HCCA, provides that consent be obtained from capable patients² and otherwise, from their substitute decision-makers (SDMs). There is considerable variability between provinces in the components of the pre-planning process, which may include ACP conversations, and/or GOC discussions, as well as potential documentation of the outcomes of either or both. In Ontario, pre-planning is limited to the expression of wishes, values and beliefs as they relate to future health treatments and care. On the other hand, consent requires any health care decision (as distinguished from wishes) to be given only after the patient received information about their health condition and treatment options. This requirement helps to protect patient's rights and ensure that health decision-making, whether by a patient, or the incapable patient's SDM is always done in context and with full information.

Across health settings, health practitioners, health care managers, ethicists and others have developed policies, practices and associated forms which encourage or require patients (or their SDM) to articulate their preferences for future health care. This push for pre-planning has extended across the many settings where health services are provided, including hospitals, primary care, long-term care (LTC) and home care. Unfortunately, it is clear that not all elements of this pre-planning comply with applicable health legislation and reflect the limits prescribed by the law.

Many initiatives have been set up to promote various forms of pre-planning including the National Speak Up Campaign by the Canadian Hospice Palliative Care Association (CHPCA), and HCC and ACP education projects in several Local Health Integrated Networks (LHINs) (including Erie-St Clair, Waterloo-Wellington, Hamilton, Norfolk, Haldimand and Brant). The Canadian Frailty Network, formerly known as Technology Evaluation in the Elderly Network, a federal Centre of Excellence, has funded a variety of clinical research projects by health practitioners and academics focused on ACP tools. Many hospitals, individual LTC homes and chains, and other health team groups such as Health Links have developed or are working on policies and forms for informed consent, ACP and GOC.

² The words "patient" and "person" have both been used interchangeably 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 HCCA.

From the perspective of the health regulatory Colleges, the College of Physicians and Surgeons of Ontario (CPSO) and the College of Nurses of Ontario (CNO) (amongst others) have created, or are in the process of revising, policy statements on end-of-life care that include information on ACP. Hospice Palliative Care Ontario (HPCO) has established a HCC and ACP Leadership Table and Community of Practice to engage in a variety of tasks related to HCC and ACP including the review of forms, policy and practice statements. Various health care associations, including the Ontario Hospital Association (OHA) and the Ontario Association of Non-Profit Homes and Services for Seniors (OANHSS) have hosted conferences on these issues.

While a diversity of HCC, ACP and GOC policies, toolkits and forms (which we will generally refer to as “practice tools”) have been developed in Ontario, there is limited research evaluating their use, or whether these practice tools appropriately reflect the current legal landscape. The focus of this research paper is to gain a better understanding of current HCC, ACP and GOC practice tools used across the province, to explore how these are implemented, and to determine whether they support decision-making for end-of-life care in the appropriate legal framework. This includes:

- the linkages between informed consent, ACP, substitute decision-making and GOC;
- assessing whether the creation of standardized practice tools would (or would not) be beneficial in this context;
- which organizations should be responsible for any such practice tools, such as government, health regulatory Colleges, Local Health Integration Networks, Health Links and/or others;
- what any “package” of such practice tools would be comprised of; and
- how practice tools could best be implemented across Ontario’s diverse care settings.

A. Limitations

This research paper has a number of limitations:

1. Practice Tools May Not Be Representative

First, the sample of practice tools may not be representative in all instances. The scoping of tools was intentionally broad, aiming to capture the diversity across multiple health care settings; however, this does not create depth in a review of tools from one type of health care setting or for particular health practitioners.

Additionally, health practitioners and organizations were invited to send materials for the purpose of review and assessment. Given this self-selection process, it is possible that only practice tools believed to be in alignment with the legal framework were submitted, resulting in an underestimation of the number of errors or issues with existing tools. For example, one major health care organization that did not offer any materials indicated that they did not have any practice tools of any type although it is likely that the organization does use forms for consent and likely would have institutional policies on these issues.

Further, not every tool examined was constrained for use in end-of-life settings. For example, the requirement for informed consent applies for any health care decision, not just at end-of-life.

2. *Lack of Literature and Research*

Second, our evaluation of the implementation of practice tools is limited by the lack of literature and research assessing the use and the effectiveness of practice tools in Ontario. While we were able to explore perceptions of the implementation and efficacy of practice tools, these only represent the perspectives of the individuals who participated in our interviews and focus groups. We cannot comment on the understanding or competencies of health care staff implementing practice tools.

Further, we did not explore knowledge translation strategies, making it difficult to know whether practice tools were accompanied by education, or training to ensure appropriate understanding and implementation of the tools. Additionally, we cannot comment on whether these tools ensured meaningful decision-making due to the lack of patient outcome measures.

3. *Limited Scope*

This research paper has a limited scope. While we recognize that funding impacts practices (including the use of tools), due to the complexities surrounding funding for health practitioners, this research paper does not discuss billing or fee codes. Nor does it address cultural differences among health practitioners and health care organizations. It also does not look at practice tools embedded in electronic health records developed for consent, ACP or GOC. We have not researched whether that work, which is in progress, appropriately reflects Ontario law on these issues. Finally, as readers may be aware, major legislative changes have recently occurred in Canada with the enactment of federal Bill C-14 amendments to the

Criminal Code,³ legalizing medical assistance in dying (MAID). Even at this early stage, new tools are being developed. However, given the timing and scope of this research paper, no specific analysis of MAID practice tools has been done. Acknowledging the above limitations help to stress that this research paper is illustrative of only some of the challenges, providing a snapshot of the types of practice tools currently in use in Ontario and their relative strengths and weaknesses.

II. BACKGROUND

A. HCC and ACP in Ontario – The Legal Framework

Before review and discussion of the practice tools, and whether and how these tools support appropriate health care decision-making, it is necessary to understand the legislative framework against which the tools were compared and evaluated for this paper. This will explain the linkages between informed consent, ACP and substitute decision-making.

1. An Overview of Person Centered Decision Making in Ontario

In Ontario, ACP, GOC, and HCC are situated along a continuum that comprise the person-centered decision making process. To illustrate the connection between ACP, GOC and HCC, Dr. Jeff Myers and Dr. Nadia Incardona created the following diagram.⁴ This diagram also provides an accurate pictorial representation of the legal framework in Ontario.

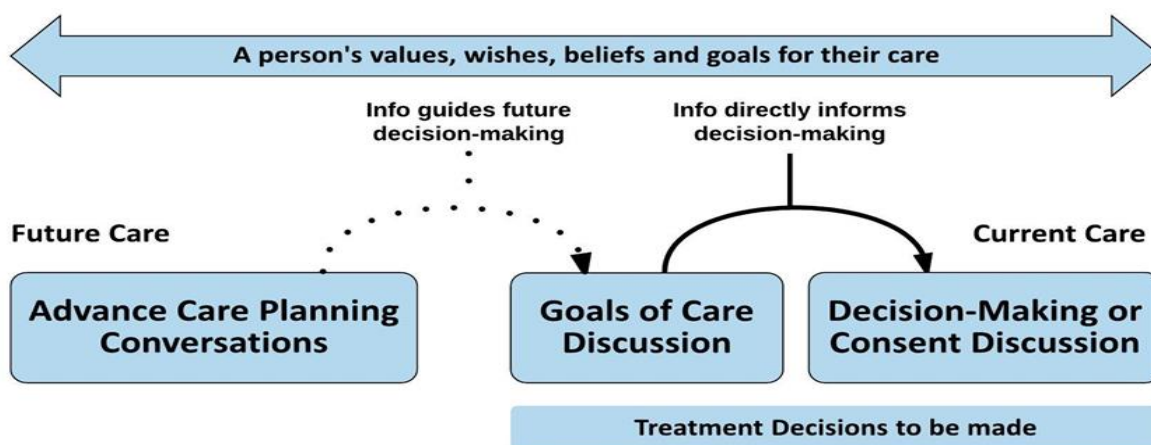


Figure: Relationship between three discussions that contribute to informed consent




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³ *Criminal Code*, RSC 1985, c C-46, as amended by Bill C-14.

⁴ Myers, Jeff and Nadia Incardona. “Advance Care Planning Conversation Guide: Clinician Primer”, online: Conversation Guide. <<http://acpww.ca/wp-content/uploads/2016/01/ACP-Conversation-Guide-Clinician-Primer.pdf>>.

These physicians along with Dr. Leah Steinberg have also developed the following chart, as an educational tool to summarize the clinical context of ACP, GOC discussions and decision-making (informed consent) discussions. It has proven to be an effective means for teaching physicians and other health practitioners the linkages between these three processes.

	Clinical Context	Outcome is...	Outcome is NOT...	How goals are defined
Advance Care Planning	Future	Values & wishes prepare SDM(s) for future decision-making	Code Status, POLST, etc.	Patient is to define and describe
Goals of Care Discussion	Current	Patient understands illness Clinician understands patient's values & goals	Code Status, POLST, etc.	Patient is to define and describe
Decision-making Discussions	Current	Care or treatment decision(s) e.g. code status, POLST, etc.		Treatment oriented e.g. cure, resuscitation, comfort

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This is a brief explanation of the chart.

ACP conversations focus on the patient, when capable, communicating what is important to them, with respect to their health care and health condition. Described as “values and wishes” in the chart, the patient communicates these to the person or persons who would be their substitute decision makers (SDM) in the future when they may become incapable for treatment decision making. The outcome of these conversations is not a code status or other form that may record decisions of the patient about specific treatments.⁵ These conversations are future focused and not about present care. What is expressed and discussed is defined by the patient and focuses on what they want to communicate. The values and wishes communicated by the patient are not directions for the clinician.

GOC discussions focus on ensuring the patient understands their illness, and helping the health practitioner to understand who the patient is, and how that patient defines the goals they have for their care. The outcome of these discussions is again not a code status or consent to a particular treatment. These discussions are intended to elicit what the patient wants to achieve as a result of treatment or care that may be provided to them. As such, the goals of care

⁵ The POLST (Physicians Orders for Life Sustaining Treatment form) referenced in the chart is an example of a particular type of form that records the informed consent of patients to certain treatments. It is completed by the physician after discussion with the patient and creates medical orders that other clinicians would also follow when providing care to that patient. More information on the POLST is available at <http://polst.org/about-the-national-polst-paradigm/what-is-polst/>

discussion prepares the patient and the health practitioner to engage in subsequent decision making and the consent process.

The decision-making discussions result in what is recorded or understood as the informed consent by the patient to a treatment or plan of treatment. The outcome of these discussions are treatment decisions and may also include physician orders.

This chart should be kept in mind when reading the detailed explanation of the legislative framework that follows.

2. Informed Consent

At common law and under Ontario legislation, informed consent is required before a health practitioner can provide treatment to a patient.⁶ While there are exceptions to the requirement to obtain informed consent, these are narrow and time-limited (e.g. in an emergency, special rules apply). The Ontario government codified and added provisions about substitute decision-making to the common law of consent by passage of the 1992 Consent to Treatment Act,⁷ which was repealed a year later. It was replaced by the HCCA which was substantially the same in respect to the sections on consent.⁸

Section 10 of the HCCA states that when a health practitioner proposes a treatment, the health practitioner must get consent before administering that treatment. Consent for the proposed treatment must come from the patient if capable, or if incapable (according to a legal test) from the patient's SDM.⁹

The health practitioner must therefore understand consent and take the necessary steps to get that decision (i.e. the patient's agreement or refusal to proceed with the treatment). An important step is determining whether the patient, or the patient's SDM, will make the treatment decision. This requires assessing whether the patient is capable to make the particular treatment decision. If the patient is incapable to make the decision, the health practitioner must turn to the patient's legally authorized SDM, discussed further below.

⁶ HCCA, *supra* note 1, s.10(1).

⁷ *Consent to Treatment Act, 1992, S.O. 1992, c. 31.*

⁸ Decisions under the HCCA apply to treatment, admission to a care home (i.e. long-term care home) and personal assistance services). Informed consent is required in all of these cases, and there is a process for each to determine an individual's capacity to give consent, as well as to who may make a decision on behalf of an incapable individual. This paper focuses on practice tools related to informed consent to treatment and ACP only.

⁹ HCCA, *supra* note 1, s.10(1).

In effect, there is no SDM until the patient is found incapable to make the treatment decision. Further, a capable patient may not delegate treatment decision-making authority to a third party, such as a close relative. For example, if a patient says, “just ask my son to make the decision”, the health practitioner may encourage the patient to consult with her son; ultimately, however, the decision will be the patient’s.

i. Elements of Consent

The elements of consent are:

1. It must relate to the treatment.
2. It must be informed.
3. It must be given voluntarily.
4. It must not be obtained through misrepresentation or fraud.¹⁰

*Reibl v. Hughes*¹¹ is the legal case that established the requirement for informed consent to treatment in Canada. It stands for the proposition that the information provided to a patient must be grounded in what a reasonable person would do when informed of the risks of proceeding:

An alternative to the subjective test is an objective one, that is, what would a reasonable person in the patient’s position have done if there had been proper disclosure of attendant risks.¹²

The legislative response in light of these new rules established in *Reibl* was to set out, in the HCCA, the elements of consent. Consent is informed if, before giving it, the person giving consent (i.e. capable patient or otherwise, SDM) received information about:

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.¹³

¹⁰ HCCA, *supra* note 1, s.11(1).

¹¹ *Reibl v. Hughes* [1980] 2 SCR 880, 114 DLR (3d) is the leading case on informed consent in Canada, and created a standard of what a reasonable person would want in the circumstances.

¹² *Ibid.*, p. 898.

¹³ HCCA, *supra* note 1, s.11(3).

and “the person received responses to his or her requests for additional information about those matters”.¹⁴

ii. Defining Treatment and Plan of Treatment

Consent may be to a treatment or to a plan of treatment. Treatment is defined in the HCCA as:

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.”¹⁵

A plan of treatment refers to a plan that,

is developed by one or more health practitioners, 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 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.¹⁶

One health practitioner may, on behalf of all the health practitioners involved in a plan of treatment, propose the plan of treatment, determine capacity of the patient for the plan of treatment, and get informed consent or refusal of consent from the patient for the treatments

¹⁴ Ibid., s.11(2)(b).

¹⁵ HCCA, *supra* note 1, s. 2 (1).

¹⁶ HCCA, *supra* note 1, s. 2(1).

for which he/she is capable and from the patient's SDM for the treatments in the plan for which the patient is not capable.¹⁷

Of note, a plan of treatment can be important in the context of end-of-life, as it provides an opportunity for either the capable patient, or if incapable, the SDM, to consent to treatment taking place in the future - including the withholding or withdrawal of treatment in light of the person's current condition. This is not an "advance consent" because the patient or SDM does not have the information necessary to make an informed decision that is related to the patient's current condition. It is a contextualized decision. This is quite different than a capable patient expressing wishes for future care, which does not include the context of full information about a future clinical condition.

iii. Presumption of Capacity and Manner of Consent

Consent to treatment may be express or implied.¹⁸ Unless it is not reasonable to do so in the circumstances, a health practitioner is entitled to presume that consent to a treatment includes:

- a) consent to variations or adjustments in the treatment, if the nature, expected benefits, material risks and material side effects of the changed treatment are not significantly different from the nature, expected benefits, material risks and material side effects of the original treatment; and
- b) consent to the continuation of the same treatment in a different setting, if there is no significant change in the expected benefits, material risks or material side effects of the treatment as a result of the change in the setting in which it is administered.¹⁹

iv. Legal Test for Capacity

The health practitioner offering the treatment is responsible for the determination of whether the patient is capable for that decision.²⁰ In order to be capable to make treatment decisions, a person must meet both prongs of the following test:

¹⁷ HCCA, *supra* note 1, s. 13.

¹⁸ HCCA, *supra* note 1, s. 11(4).

¹⁹ HCCA, *supra* note 1, s. 12.

²⁰ HCCA, *supra* note 1, s. 10(1).

1. Able to understand the information that is relevant to making a decision about the treatment; and
2. Able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.²¹

There is a presumption of capacity with respect to treatment, unless the health practitioner has reasonable grounds to believe that the patient is incapable with respect to the treatment.²² The health practitioner must get a decision from a capable patient or if incapable, the patient's SDM. This is a contextualized decision that is obtained after the patient or SDM is provided with the information about the patient's condition, the treatment options, and information required for consent.

v. Rights Information versus Rights Advice

If the health practitioner decides that the patient is incapable for a particular treatment decision, the health practitioner must provide that person with rights information as specified by their particular professional governing body.²³ This includes information about the patient's right to apply to the Consent and Capacity Board to ask for a review of that finding of incapacity. (This is also different than the information a rights adviser must provide to an individual under the *Mental Health Act*,²⁴ which is provided in the case of multiple changes of legal status, such as treatment incapacity, incapacity to manage property, capacity to consent to a community treatment plan, among others.)

If the person indicates that he or she intends to apply to the Board to challenge a finding of treatment incapacity and it is not otherwise prohibited or the alleged incapable patient or another person applies or indicates the intention to apply for an appointment of a representative for the patient, treatment must not begin:

- a) until 48 hours have elapsed since the health practitioner was first informed of the intended application to the Board without an application being made;
- b) until the application to the Board has been withdrawn;

²¹ HCCA, *supra* note 1, s. 4(1).

²² HCCA, *supra* note 1, s. 4(2) & (3).

²³ HCCA, *supra* note 1, s. 17.

²⁴ *Mental Health Act*, R.S.O. 1990, c. M.7 (MHA).

- c) until 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.²⁵

The patient or the incapable patient's SDM may withdraw the consent to the treatment at any time after giving consent.²⁶ This includes to a plan of treatment (which of course falls under the definition of "treatment" under the HCCA).

vi. Emergency

In an emergency, health practitioners may provide treatment to a patient without consent. There is an emergency "if the person for whom the treatment is proposed is apparently experiencing suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm".²⁷ In providing treatment in an emergency, health practitioners are required to follow any known wishes of the patient applicable to the circumstances. They are prohibited from administering a treatment in the emergency if the patient who at the time of making a prior capable wish was at least 16, and has stated that he or she did not want to receive the proposed treatment.²⁸

Further, if an SDM refuses treatment for the patient in an emergency, the health practitioner may treat despite the refusal if the health practitioner proposing the treatment believes that there is an emergency and is of the opinion that the SDM is not complying with s. 21 of the HCCA.²⁹ Emergencies are the only time that health practitioners in Ontario follow and interpret

²⁵ HCCA, *supra* note 1, s. 18(3).

²⁶ HCCA, *supra* note 1, s. 14.

²⁷ HCCA, *supra* note 1, s. 25(1).

²⁸ "Wishes" are explained in the section on Advance Care Planning.

²⁹ HCCA, *supra* note 1, s. 21 sets out the principles that the SDM must follow in giving or refusing consent. The SDM must make decisions for the patient when incapable by following any wishes expressed when capable expressed by the patient when capable that are applicable to the decision at hand. If the SDM does not know of a

the patient's ACP wishes directly.³⁰ In other circumstances, the health practitioner must get the consent or refusal of consent from the SDM, if the patient is incapable to provide consent.

The fact that a health practitioner may follow wishes of the patient, expressed when capable, in a subsequent emergency, raises the importance of health practitioners communicating with patients how any wishes they make could be relied on in practice. In short, a given wish may have serious consequences for a patient.

3. Advance Care Planning

The term "advance care planning" (or ACP, as defined above) does not appear in the HCCA. The specific origin of this term is unknown. The term is used in different ways in different jurisdictions. Some researchers include helping patients understand their illness and treatment options under the rubric of ACP; however, in Ontario those are more appropriately fundamental elements of health care decision-making. Some health practitioners refer to ACP as setting "goals of care" (GOC, as defined above) although others would argue that GOC is a separate process that informs the consent process. Since the law on health care decision-making is provincial, even across Canada it is difficult to use research or practice tools on ACP from other provinces, unless the differences between the various laws are identified and taken into consideration. While ACP practice tools from other jurisdictions may have value, it is imperative that they be adapted before being used in Ontario.

The term "advance care planning" has become popularized and it is used in research as though it has a specific meaning; for these reasons, it is important to define the Ontario version of ACP very carefully, using the Ontario legislative framework.

In most jurisdictions, ACP is described as choosing a proxy decision-maker to make decisions for a patient who is incapable. In Ontario law, this proxy role is provided for in the HCCA in the hierarchy of SDMs for health care and in the *Substitute Decisions Act*³¹ in the sections related to powers of attorney for personal care (POAPCs). Some jurisdictions include in ACP some form of document (a "directive") that may or may not stand alone as the patient's instructions about their future care for the proxy to follow. Some jurisdictions also require or permit health practitioners to directly follow these instructions without getting an informed consent from the proxy.

wish applicable to the circumstances or if it is impossible to comply with the wish, the SDM is required to act in the incapable person's best interests. "Best interests" is defined in HCCA, *supra* note 1, s. 21(2).

³⁰ HCCA, *supra* note 1, s. 26.

³¹ *Substitute Decisions Act*, 1992, S.O. 1992, c. 30 (SDA).

Ontario's version of this is different. Ontario law is based on a substitute decision-making scheme as described above, rooted in a requirement for informed consent even if the health practitioner has knowledge of the patient's uncontextualized and uninformed directions. A patient cannot "pre-consent" to a future treatment. A patient can communicate to his or her future SDM what kind of care he or she may want under various circumstances. The SDM uses these expressions to guide them in making health care decisions on behalf of the incapable patient.

The HCCA uses the word "wishes" to refer to patient statements that do not meet the standard for an informed consent to treatment. Specifically, if there is no proposed treatment on the table, and the criteria for informed consent have not been met. A patient may express "wishes" that reflect their feelings or initial thoughts about potential treatments, should they one day need such a treatment. Consequently, wishes are not "decisions", but rather they are speculative statements.

The HCCA also refers to patients' "values and beliefs" that may be communicated to and considered by the SDM. This combination takes the wishes beyond statements about specific treatments which cannot always be anticipated. Considered together, wishes, values and beliefs permit and guide the SDM to think about who the patient is and more importantly, what they would take into account when making decisions for themselves. This is arguably a more patient-centred approach to proxy decision-making than captured in the law of some other jurisdictions.

The HCCA does not require any specific documentation for these wishes. Patients have the ability to communicate different wishes for future care as they experience their changing health. Wishes in Ontario may be expressed orally, put in written form or communicated in any way the patient uses to communicate to others. Therefore, ACP has been described in Ontario as a process that involves the capable patient:

1. *Identifying his or her future Substitute Decision-Maker*, by either:
 - a) Confirming that he or she is satisfied with his or her default/automatic SDM in the hierarchy list that is in section 20 of the HCCA

OR

 - b) Choosing someone specific to act as an SDM by preparing a POAPC naming that person

2. *Expressing his or her 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.³²

What does this mean in practice? The next two sections provide an explanation about these two parts that make up ACP in Ontario.

i. Confirming or Choosing an SDM

Section 20 of the HCCA provides a hierarchy of SDMs, as follows:

1. Guardian of the person with authority to give or refuse consent to treatment
2. Attorney for personal care with authority to give or refuse consent to treatment
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child or parent or Children's Aid Society (person with right of custody)
6. Parent with right of access
7. Brother or sister
8. Any other relative³³
9. Office of the Public Guardian and Trustee (OPGT)³⁴

The first three levels require that someone actively take a step to seek the authority to become an SDM:

1. Someone other than the incapable person must apply to the Superior Court to be appointed as guardian³⁵
2. A person while capable may prepare a Power of Attorney for Personal Care to appoint one or more persons to be his or her attorney(s).³⁶
3. A person who is 16 years old or older and who is incapable with respect to a proposed treatment (or anyone else, such as a friend or family member of the

³² The Advocacy Centre for the Elderly (ACE) has used this explanation of ACP since 2005 in any papers written by ACE staff and in all continuing professional and public legal education sessions on HCC and ACP.

³³ HCCA, *supra* note 1, s. 20(1).

³⁴ HCCA, *supra* note 1, s. 20(5).

³⁵ SDA, *supra* note 27, s. 55(1).

³⁶ *Ibid*, s. 46(1).

person incapable for treatment) may apply to the Consent and Capacity Board to appoint a representative to give or refuse consent on the person's behalf.³⁷

For the most part, the remaining levels in the hierarchy are the automatic SDMs who have the right to act as SDM simply because they are a family member of the incapable person or otherwise have authority from having custody of the person (Children's Aid Society). The OPGT is the last resort SDM, stepping in to provide or refuse consent only if there is no higher-ranking person in the person's life that meet the requirements to be the SDM.

The person or persons who are highest-ranking in this hierarchy and who meet the requirements to be an SDM would be the SDM for the incapable patient. The requirements to be an SDM are in section 20(2) of the HCCA. The person must be:

- a. Capable with respect to the treatment;
- b. At least 16 years old unless the parent of the incapable person;
- c. Not prohibited by a court order or separation agreement from acting as SDM;
- d. Available; and,
- e. Willing to act as an SDM³⁸

If a particular person does not meet these requirements at the time a treatment decision is required for the incapable patient, that person is dropped from the hierarchy for that particular decision. If that same person meets the requirements to be an SDM at a future date when another decision needs to be made for the patient, the SDM for the patient then may change. The health practitioner must apply the requirements to determine who has authority to act as an SDM at the time a treatment decision needs to be made for the patient.

If there are multiple SDMs at any step in the ranking, all of them would be entitled to act as an SDM for the patient. They may agree amongst themselves that one or more of them will act instead of all of them, but that is a decision equally-ranked SDMs must make together. Health practitioners may not unilaterally pick one SDM to act for the group of equally-ranked SDMs. For example, an adult child who lives locally cannot be relied on by a health practitioner, over two others who live out of town and who wish to participate fully in decision-making.

³⁷ HCCA, *supra* note 1, s. 33(1); note as well that the application for appointment of a representative cannot be made if the incapable person has a guardian who has authority to give or refuse consent to the proposed treatment, or an attorney for personal care under a power of attorney conferring that authority, s. 33(3).

³⁸ HCCA, *supra* note 1, s. 20(2).

If multiple equally-ranked SDMs who all wish to act as SDMs together cannot agree on a decision for the incapable patient, the health practitioner must turn to the OPGT to make the decision.³⁹ The health practitioner is not entitled to turn to the next highest-ranking SDM. An exception to turning to the OPGT would be if a POAPC prepared by the patient while capable sets out a scheme to deal with conflicts between multiple attorneys. For example, the POAPC may name three attorneys to act jointly or severally, but may also contain a clause that states that for any decision where they cannot all agree, the majority may decide. Except for this type of example, the health practitioner cannot choose amongst the disagreeing SDMs.

The automatic SDMs are primarily family members of the patient. The OPGT has authority automatically under the legislation without a court order as the last resort decision-maker who must step in if no one higher ranking in the patient's life is found to act as an SDM. This automatic hierarchy ensures that every person in Ontario has an SDM for health treatment even if the patient has done no pre-planning. This also means that health practitioners do not make treatment decisions for patients. If a patient is incapable, the health practitioner always has someone to turn to, to obtain an informed consent, subject to the emergency exception.

ii. "Wishes", Values and Beliefs

The word in the HCCA that describes what the patient expresses to their future SDMs to guide that SDM in making decisions for the patient when incapable is "wishes".⁴⁰ This word is not specifically defined in the legislation.

The word "wishes" does not appear in the sections on the requirements for consent. It must have a different meaning than consent, which is a contextualized decision. The fact that the word "wishes" appears in the section on emergency treatment also supports the interpretation that the word "wishes" in the HCCA is a statement made speculatively, without full information, as the wish is being followed when there is no time to get an informed consent. This also emphasizes that wishes are still important although not fully informed.

The word "wishes" also appears in section 21 of the HCCA, which describes the principles that an SDM must follow in giving or refusing consent on behalf of an incapable person. If the SDM knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the SDM is required to give or refuse consent in accordance with the wish.⁴¹ If the person changes their wishes over time, the SDM is required

³⁹ HCCA, *supra* note 1, s. 20(6).

⁴⁰ HCCA, *supra* note 1, s. 5.

⁴¹ HCCA, *supra* note 1, s. 21(1).

to follow the most current capable wishes because “later wishes expressed while capable prevail over earlier wishes”.⁴² If the SDM does not know of any wishes applicable to the circumstances, or only knows of wishes that are impossible to comply with, the SDM is required to act in the incapable person's “best interests.”⁴³

Best interests is defined in the HCCA as:

- 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.⁴⁴

There is guidance in case law on the requirement of the SDM to interpret the patient’s wishes and when best interests come into consideration.

In the case *Conway v. Jacques et al*,⁴⁵ the Court of Appeal noted that the HCCA was the Ontario Legislature's response to the successful *Charter* challenge in *Fleming v. Reid*. In *Fleming v. Reid* the Court of Appeal struck down legislation allowing an SDM to consent to treatment as being the patient’s best interests without regard to the patient’s prior wishes and without a right to a hearing.⁴⁶ Sharpe, J.A. states:

The (Health Care Consent) Act requires close attention to the patient's wishes by those who make treatment decisions on the patient's behalf. The wishes of the

⁴² HCCA, *supra* note 1, s. 5(3).

⁴³ HCCA, *supra* note 1, s. 21(1) &(2).

⁴⁴ HCCA, *supra* note 1, s. 21(2).

⁴⁵ *Conway v. Jacques et al*, 59 O.R. (3d) 737 at para 29, 214 D.L.R. (4th) 67.

⁴⁶ *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (C.A.) at Part Viff, 28 A.C.W.S. (3d) 238.

patient are to be considered by the substitute decision-maker at two stages under the Act:

1. in acting in accordance with a prior capable wish applicable to the circumstances pursuant to s. 21(1)1; and
2. in determining the incapable person's best interests pursuant to s. 21(2) where there is no prior capable wish applicable to the circumstances.

At the first stage, the substitute decision-maker must act in accordance with a wish expressed while capable that is applicable to the circumstances. However, I agree with the appeal judge that 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.⁴⁷

At paragraph 32 he further states:

At the second stage, the substitute decision-maker must decide whether or not to consent to treatment on the basis of the best interests test under s. 21(2). Under s. 21(2)(b), the substitute decision-maker must take into account "any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under s. 21(1)1", namely any wishes that are not prior capable wishes applicable to the circumstances. It is only at the second stage that the Act allows for consideration of the decision the patient would have made in light of changed circumstances.⁴⁸

He continues: "If a prior capable wish is not applicable to the circumstances, the question for the SDM is not what the patient would have decided in light of the change, but rather what is in the best interests of the patient."⁴⁹ The Consent and Capacity Board has also provided some guidance on how to determine if a wish is "applicable under the circumstances." *In the Matter of Ms. M.F.*, Mark Handelman, then Vice Chair and Senior Lawyer Member, stated:

...what is the nature of wish the legislation contemplates? According to s 42(1), it is a wish 'applicable to the circumstances.'⁵⁰ 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.⁵¹

⁴⁷ *Ibid.*

⁴⁸ *Ibid* at para. 32.

⁴⁹ *Ibid* at para. 33.

⁵⁰ HCCA, *supra* note 1, s. 42(1).

⁵¹ *Ms. M.F.* (Case TO031106), 2003 CanLII 54897 (ON Consent and Capacity Board) at p. 7.

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.⁵²

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."⁵³

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 timeframes 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 an SDM 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 may apply. Life can be unpredictable.⁵⁴

In the first two cases, the wish and the circumstances to which it applies are concrete. In the third, 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.⁵⁵ The wish needs a framework of relevance to the time it might be implemented.⁵⁶

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

⁵² *Ibid.*

⁵³ *Ibid.*

⁵⁴ *Ibid.*

⁵⁵ As noted throughout this research paper, the term "advance directives" is not a term found in Ontario legislation; it was likely used here interchangeably with "wishes".

⁵⁶ *Ibid.*

adherence. Such general outlines of preference may, as life unfolds, not be applicable to the circumstances.⁵⁷

Therefore under Ontario law, when the SDM gives substitute consent to treatment, the SDM is serving as the “interpreter” of the patient's wishes, values and beliefs and must determine:

1. whether the wishes of the patient were expressed when the patient was still capable (and were expressed voluntarily);
2. whether the wishes are the last known capable wishes of the patient;
3. what the patient meant in that wish;
4. whether the wishes are applicable to the particular decision at hand;
and,
5. If there are no applicable/capable wishes, how the patient’s values, beliefs, and incapable/inapplicable wishes would apply to the patient’s best interest.⁵⁸

An SDM may also apply to the Consent and Capacity Board to get directions about the wishes or to depart from the wishes. This can occur if it can be argued 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.⁵⁹

Just because a person is determined to be incapable to make a treatment decision, he or she may still express a form of “wishes”, indicating some type of preference or choice.⁶⁰ As that person is not decisionally capable, and wishes that the SDM must follow must be expressed by the person when capable,⁶¹ the health practitioner must turn to the patient's SDM for treatment decisions. The SDM is still required to consider those incapable wishes when deciding what is in the best interest (a term defined in the HCCA) of the person, but is not required to make treatment decisions in accordance with the incapable wishes. The incapable wishes do not take priority over the other elements of best interests.

When the person is incapable and expressing preferences or choices, the health practitioner is required to turn to the SDM for treatment decisions. This requirement is not in conflict with the Residents Bill of Rights in the *Long-Term Care Homes Act* (LTCHA) or the Bill of Rights in the

⁵⁷ *Ibid.*

⁵⁸ HCCA, *supra* note 1, s. 21(1).

⁵⁹ HCCA, *supra* note 1, s. 35(1).

⁶⁰ HCCA, *supra* note 1, s. 21(2)(b).

⁶¹ Wishes defined, HCCA: “A person may, while capable, express wishes with respect to treatment, admission to a care facility, or a personal assistance service.” See HCCA, *supra* note 1, s. 5(1).

Home Care and Community Services Act, 1994. Both state that the resident or the person receiving community services has the right to participate in the development of their plan of care or plan of service and the right to give or refuse consent to any element of the plan of care or service.⁶² If a person lacks decisional capacity for a particular treatment or care decision, the SDM exercises the rights of the resident or the person receiving the services.

The incapable wishes or preferences may be relevant to the health practitioner or service provider. Specifically, the reaction of the incapable person to the delivery of the care or treatment needs to be factored in when determining how to provide the care, treatment of service, or whether alternative care, treatment or services should be discussed with the SDM. This is distinct from who has authority to provide the consent or to refuse the treatment.

ACP wishes are not consents. This is different than in those jurisdictions where documents are intended to provide instructions directly to the health practitioner. Specifically, the HCCA, which governs consent to treatment in Ontario, does not refer to “advance directives”. Instead, the legislation was drafted to ensure that patients could express wishes, and in this way, engage in ACP. The framework created a system of substitute decision-making in which a person (the SDM), and not a piece of paper, would be required to give or refuse consent if the patient became incapable.

The HCCA states that the wishes may be expressed orally, in a POAPC, in any other written form, or in any other manner that the patient uses to communicate.⁶³ Later wishes expressed when capable prevail over earlier wishes.⁶⁴ This would mean that wishes communicated orally after a patient has completed a POAPC or any other written document trump the written wishes. This is the key reason why health practitioners must turn to the patient, if capable, or the incapable patient’s SDM, for the consent to treatment despite the existence of the written ACP wishes. The patient may have changed his or her mind about what was written down so the health practitioner must talk to a person rather than take directions from a document. The preparation of a POAPC is part of planning for incapacity and must be done when a person is mentally capable. This is the alternative to accepting as an SDM the automatic, default SDM set out in section 20 HCCA SDM hierarchy.

ACP is a voluntary process. A person may decide not to express ACP wishes because he or she has specific religious or cultural beliefs and feels that ACP is in contradiction to these beliefs.

⁶² *Long-Term Care Homes Act, 2007* SO 2007, c 8, s. 3(1)(11); *Home Care and Community Services Act, 1994*, SO 1994, c. 26, s. 3(1).

⁶³ HCCA, *supra* note 1, s. 5(2).

⁶⁴ HCCA, *supra* note 1, s. 5(3).

Some persons may choose not to engage in this process because they are superstitious and think it may be “tempting fate” to think about end-of-life. Others may only want to prepare a POAPC to name an SDM because of the inherent limitations of ACP. People’s wishes about future health care often change as they age or as health conditions change. Some individuals who have expressed wishes to no longer live if they suffer major injuries discover that they can live meaningfully even with a disability. Others may choose treatment and assistance that they thought earlier they would never pursue.

ACP wishes have been criticized because of vague language that leads to possible misinterpretation of wishes. In particular, it is difficult to articulate preferences for future care with enough specificity in any particular health situation, until there is context for a decision to be made. Additionally, treatments may change as science advances, and a person’s wishes may have been different if he or she could have anticipated the advances. The inherent limitations in ACP were considered when the *Consent to Treatment Act*, the predecessor legislation to the HCCA, was drafted. That is a primary reason why a substitute decision scheme was incorporated into the Ontario legislation, as opposed to a “health directives” format. This scheme was continued in the HCCA when it came into effect in 1996.

As ACP is voluntary, health care organizations and health practitioners cannot require patients to prepare POAPCs or to express or document ACP wishes (including using templates or forms) as a condition of admission to a particular facility or as a precondition to receiving a health service. Nor can a patient be required to execute a POAPC.⁶⁵

In particular, there are no requirements in legislation, regulations or standards applicable to LTC homes or hospitals in Ontario stating that they must have patients (including residents) execute written ACP wishes or DNR (do not resuscitate) or No CPR “directives” on admission or at any time after admission. It is not possible to anticipate any given illness and therefore it is impossible to express ACP wishes to predetermine all the many different types of health decisions that would need to be made if the person suddenly experienced a health crisis. There are also limitations on what a person may wish for in advance or on wishes that an SDM may follow in making some care or treatment decisions for an incapable person.

For example, in *Bentley v. Maplewood Seniors Care Society*,⁶⁶ the family of a person with advanced Alzheimer's disease who resided in a LTC home, applied to court for an order to stop the staff from feeding her in compliance with her previous expressed capable wishes. This case

⁶⁵ At DDO, health care organizations are often reminded that they cannot “require”, but they can “invite”, emphasizing the choice of the patient.

⁶⁶ *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91, 250 ACWS (3d) 347 (“*Bentley*”).

was decided in British Columbia. The laws relating to health decision-making and ACP are different than in Ontario, but some principles in this case would be applicable in Ontario.

Margaret Bentley, herself a former nurse, had prepared a document in 1991 called a “statement of wishes”. Her wishes in part were as follows:

If at such time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or ‘heroic measures.’⁶⁷

I hereby absolve all who follow these instructions to be free of any legal liability. In particular, I would request the following instructions to be carried out:

.....

No nourishment or liquids.⁶⁸

The document went even further, providing that “[i]n the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized”.⁶⁹

Her spouse (who was also named her proxy in the statement of wishes) and her adult children requested that, consistent with the previous capable wishes, the staff of the home cease feeding her because they believed that she had reached the health condition described in her statement of wishes. The home refused, and ultimately, the court upheld the home’s position that Mrs. Bentley opening her mouth and accepting food was not merely a reflexive action. Rather, the evidence was that she preferred dessert over the other food she was offered and consumed, an indication that she was capable of making a choice to eat despite her advanced condition. The provision of oral nutrition and hydration by prompting with a glass or spoon was held by the court to be a form of personal care, not health care within the meaning of British Columbia legislation. To deprive the resident of food was not legally permitted and was a denial of the necessities of life under section 215(2) of the Criminal Code.⁷⁰

The statement of wishes was determined not to be a valid advance directive or representation agreement as defined by BC law. The court went further to state:

Even if Mrs. Bentley was found incapable of making the decision to accept oral nutrition and hydration, I am not satisfied that the British Columbia legislature

⁶⁷ *Ibid*, at para 2.

⁶⁸ *Ibid*.

⁶⁹ *Ibid*.

⁷⁰ *Criminal Code*, RSC 1985, c C-46, s. 215(2).

intended to allow reference to previously expressed wishes or substitute decision makers to be relied on to refuse basic personal care that is necessary to preserve life.⁷¹

An appeal to the B.C. Court of Appeal by Mrs. Bentley's family was dismissed.

One lesson for Ontario from this case is that a wish may be made in a POAPC, but if it would be illegal to fulfil that wish, it will not be acted on. In today's context, MAID is a prime example; it may be permissible to write into a POAPC that if and when an advance wish for MAID is legal in Ontario, it should be provided. However, making a wish for something that would otherwise be illegal in no way compels fulfillment of the wish in the absence of legal authority to do so.

4. Goals of Care

Similar to “advance care planning”, the term “goals of care” (GOC) does not appear in the HCCA or in any other health care legislation in Ontario. From a legal perspective, the requirement in the legislation is for health practitioners to have conversations with patients that result in consent (a decision) to a treatment or a plan of treatment. The question then is, where do GOC fit into the legal framework for health decision-making if it is not specifically a legal concept?

The next section of the paper presents a more detailed discussion of how ACP, GOC and informed consent intersect in the law. This section is a brief review of GOC as described in medical and research literature and a proposal of where GOC should be situated with respect to HCC and ACP from a legal perspective.

A review of medical and research literature reveals that health practitioners appear to understand and apply this term in a variety of ways. This may account for the confusion when health practitioners use their own approach to GOC discussions and fail to connect this to the HCC and ACP legal framework in Ontario. To illustrate the different approaches to this concept, a few examples are provided. These examples are by no means an exhaustive review of how GOC are defined by health practitioners across the various health settings. This is a sample of some common approaches identified in the research. These include examples from other jurisdictions, mainly because the medical and research literature makes no distinction between the use of the term in different jurisdictions.

In a 2012 Vancouver Coastal Health Community Engagement Report on Care Planning in Residential Care, GOC are described as “a term used in health care to refer to the general direction for the care plan developed. GOC encompasses both the patient/family experience with

⁷¹ *Bentley, supra* note 64, at para. 8.

their illness which includes their wishes, values and beliefs, related to their care and the medical interventions which can be appropriately offered given the patient's medical status".⁷² The report describes GOC discussions as a combination of what in Ontario law would be HCC and ACP conversations. It refers to wishes, values and beliefs which would be information gathered for ACP as well as to medical interventions. It does not state that the medical interventions are consented to, but it refers to medical interventions that can be offered. This discussion of medical interventions would be part of an informed consent process in Ontario. This definition does not make a distinction between HCC, ACP and GOC. It refers to GOC as a "general direction" for the care plan. It is unclear what is meant by "a general direction".

In 2013, Vancouver Coastal Health Authority (VCHA) held a Quality Forum on GOC. A similar definition of GOC appears on the storyboard, but more explanation was provided about the difference between "levels of intervention", which are similar to levels of care forms in Ontario⁷³, and GOC. The following text appears on the storyboard:

- Residents/family members want to have more opportunities to discuss;
- Use of degree of intervention alone can be difficult to interpret in crisis situations, and result in overly aggressive medical interventions and underutilization of palliative/spiritual supports; and
- Recorded goals of care can provide a framework within which interventions can be properly assessed.⁷⁴

This explanation illustrates that at VCHA the levels of intervention are being used as consents. It would then appear that the VCHA GOC are intended to provide more context of the patient's perspective to help the health practitioners determine what treatments to deliver to the individual. However, this means GOC are being used as a replacement for an informed consent, rather than serving as a discussion with the patient or SDM which would lead to documentation of treatment decisions (consents).

⁷² Cuddington, Andi. "Goals of Care – Family and Resident Perspective on Care Planning in Residential Care", online: Vancouver Coastal Health Community Engagement Executive Summary <http://www.vch.ca/media/CE_Report-Goals-of-Care-Family-and-Resident-Perspectives-2012.pdf>.

⁷³ Level of care forms contain generalized statements about what a resident would want in the event of a sudden change in their present condition. The LOC statements usually refer to whether a resident would want to be full code and be resuscitated or whether they would want a lesser degree of intervention, the lowest level being "comfort care only".

⁷⁴ Cuddington, Andi. "The Goals of Care Project at Vancouver Coastal Health Experience Uniting Patient and Public Engagement with LEAN Thinking", online: Goals of Care Poster <[file:///C:/Users/Student/Downloads/goals%20of%20care%20poster%20final%20\(2\).pdf](file:///C:/Users/Student/Downloads/goals%20of%20care%20poster%20final%20(2).pdf)>

The Carenet “Just Ask” 2013 study on discussions of GOC with patients in hospitals with serious illness describes GOC as ACP.⁷⁵ The researchers state that: “the focus of our review is to provide guidance for ACP as it pertains to the inpatient setting (i.e., determination of goals of care for the patient in hospital)”.⁷⁶ However, the recommendations of this study include this conclusion:

Decisions about goals of care should be clearly documented in the medical record and include the values that have informed these choices by using examples and the patient’s own words. Such a record maximizes the likelihood that a patient’s previously expressed wishes will be successfully translated into actual care received. Many jurisdictions are adopting standardized forms or order sets (e.g., Goals of Care Designations in the Calgary Zone of Alberta Health Services; Medical Orders for Scope of Treatment in the Fraser Health Authority, British Columbia) to provide clear documentation of the types of life-sustaining treatment wanted or not wanted by a patient’.⁷⁷

This appears to suggest that GOCs are being used as consents (in the legal sense) for particular interventions such as resuscitation or hospitalization. However, this may not comply with the requirement for consent to be specific to a treatment or to be informed. The Just Ask Conversation Guide for Goals of Care Discussions and the Carenet website page on the Just Ask Campaign describe the GOC discussion in a different way, making a distinction between ACP and GOC and consent decisions. The website states:

This Guide provides a framework including 'scripts' to assist you with engaging patients and/or their substitute decision makers (in the case of an incapacitated patient) in goals of care conversations that lead to medical orders for the use or non-use of life-sustaining treatments.

This communication process is different from ACP, which is a communication process wherein people plan for a time when they cannot make decisions for themselves. ACP includes reflection on and determination of a person's values and wishes or preferences for care at end-of-life. These expressions are generally made outside of the clinical context and are not to be misconstrued as medical decisions. A medical decision requires consideration as to whether the wishes and preferences are clinically indicated.⁷⁸

This description has GOC discussions leading to medical decisions (which would be informed consents in the legal framework). However, the Just Ask campaign focuses on GOC discussions

⁷⁵ You, John J. et al. “Just ask: discussing goals of care with patients in hospital with serious illness” on behalf of the Canadian Researchers at the End of Life Network (2014) 186(6) *CMAJ* 425.

⁷⁶ *Ibid.*

⁷⁷ *Ibid.*, p.430.

⁷⁸ “Just Ask: A Conversation Guide for Goals of Care Discussions”, Canadian Researchers at the End of Life Network (CARENET) online: CARENET <<http://www.thecarenet.ca/just-ask>>.

that lead to medical orders for the use or non-use of life-sustaining treatments, rather than GOC that lead to a plan of treatment that includes all the treatments that need to be considered for the patient.

The Carenet Just Ask researchers point to the forms used in Alberta, which refer to GOC as both ACP and as medical orders. The website for My Health Alberta has a page titled “Advance care planning” on which the GOC are described as follows:

Goals of Care Designations are instructions that guide your healthcare team about the general focus of your care, and where you might want that care. After speaking with you and/or you and your agent, a doctor or nurse practitioner will write your Goals of Care Designation as a medical order⁷⁹

Alberta Health therefore does not make distinctions between ACP and GOC, but combines them. It is using the GOC discussion to complete a more detailed level of care form than what is commonly seen in many health facilities in Ontario, but which still is a general statement about care, rather than an informed consent as it would be defined in Ontario. It should be noted that at least one hospital in Ontario uses the Alberta GOC document as a standard clinical form without having adapted it to Ontario law.

In an unpublished article on GOC, Dr. Jeff Myers identifies that there is “considerable variation among clinicians in the interpretation of the overall purpose, expected outcomes and approach to the GOC discussion.”⁸⁰ In his review, he concludes that the research reveals two different “conceptual orientations” that have led to different ways of understanding the GOC discussion. He goes on to assert:

Some clinicians understand the purpose of the GOC discussion is to make treatment decisions. Examples of treatment-focused goals might include ‘transfer to critical care’ or ‘no resuscitation’. Contrasting this, other clinicians understand the purpose of the GOC discussion is to elicit the patient’s own personal and individualized goals for their care in preparation for subsequent decision-making. Examples of person-focused GOC might include: attending a family event, seeing the birth of a grandchild or taking a long awaited trip.⁸¹

Dr. Myers suggests that “treatment-focused GOC discussions result in decisions about direction of care (e.g. resuscitative, full medical therapy or comfort), decisions about specific treatments (e.g. code status or Physician Orders for Life-Sustaining Treatment (POLST) completion) or other

⁷⁹ Advance Care Planning Group, Alberta Health Services, “Goals of Care Designations”, online: Alberta Health Services <<https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-goals-of-care-designations.aspx>>.

⁸⁰ Jeff Myers, Leah Steinberg & Nadia Incardona, “The goals of care discussion”, unpublished paper.

⁸¹ *Ibid.*

decisions that are placed on the patient's chart (e.g. inter- or intra-institutional transfer).⁸² Alternatively, he submits that the purpose of a GOC discussion with a person-focused orientation:

...would be to prepare for decision-making by gaining an appreciation of who the person is, how their values are reflected in the goals he or she has for their care and how these align with both the clinical picture and treatment approaches being considered.⁸³

Dr. Myers describes how person-focused GOC discussions include exploring “the person's past experiences, hopes, values, priorities, perception of quality of life and what he or she considers important”.⁸⁴ Further, this type of discussion aims to clarify a person's illness understanding, and more specifically, “how the person would define and describe the goals he or she has for their care (i.e. being able to do or experience something) as well as the meaning and role for these goals.”⁸⁵ Unlike a treatment-focus GOC discussion, a person-focused GOC discussion is ‘highly individualized and different every time’. In particular, by eliciting the patient's perspective of their clinical picture, this type of GOC discussion “may illuminate misinformation and misunderstandings as well as any GOC that are incongruent or even incompatible with the clinical picture as it is understood by the clinician.”⁸⁶

He describes person-focused GOC discussions as viewing the right care for the patient as a “complex problem”. He states:

The clinician has a high degree of uncertainty as to how the discussion will achieve the outcome and about the outcome itself. As the interaction unfolds the clinician trusts the direction will declare itself, which requires both a divergent approach and an adaptive style.⁸⁷

Dr. Myers recommends health practitioners use this approach to GOC, concluding “person-focused GOC discussions are precursors and fundamental to decision-making discussions.”⁸⁸

In our view, the person-focused approach to GOC outlined by Dr. Myers is the best “fit” for the Ontario legal framework for health decision-making. It sets the GOC discussion as a means of understanding the patient better, how he or she understands their illness and what is important to them. GOC discussions are distinct from ACP conversations because they occur in

⁸² *Ibid.*

⁸³ *Ibid.*

⁸⁴ *Ibid.*

⁸⁵ *Ibid.*

⁸⁶ *Ibid.*

⁸⁷ *Ibid.*

⁸⁸ *Ibid.*

the context of the patient's present condition. A GOC discussion is not a consent discussion in and of itself, but a precursor to consent decision-making. It involves preparing both the patient and the health practitioner to take the next step towards the consent process.

B. Practice Tools to support HCC, ACP and GOC

Given the relative importance of HCC, ACP, and GOC, it is not surprising that numerous tools have been developed to support these processes. While research evaluating the use and implementation of these tools is vast, the academic literature is focused on other jurisdictions, primarily the United States. Importantly, there is a lack of research focused on evaluating the use of Ontario specific tools, or the implementation of tools from other jurisdictions that are being applied in Ontario. For the purpose of this research paper, the following types of practice tools were considered for assessment:

- a) policies, training materials, guides, and/or operational manuals that relate to consent to treatment, ACP, GOC, end-of-life care and/or substitute decision-making;
- b) documents made available to patients and/or SDMs relating to consent to treatment, ACP, GOC, end-of-life care and/or substitute decision-making (i.e. information pamphlets given to SDMs); and
- c) standardized forms, templates, tools, and questionnaires used by health practitioners to record consent, or used to guide the process or document the outcome of ACP conversations or GOC discussions (i.e. level of care, DNR, No CPR, levels of intervention, ACP forms, and consent forms).

III. METHODS

Multiple methods of data collection were used to inform this research paper, combining a review and assessment of existing practice tools, targeted interviews, focus groups, and a literature review of case law and academic articles.

To gain a better understanding of current HCC, ACP and GOC practice tools used across the province, we collected a sample of existing tools from various care settings. Some of the tools had previously been collected as part of a prior project.⁸⁹ Other tools were solicited through an

⁸⁹ Judith Wahl, Mary Jane Dykeman and Brendan Gray. "Health Care Consent and Advance Care Planning in Ontario: Legal Capacity, Decision-Making and Guardianship (January 2014)" Law Commission of Ontario Commissioned Report (LCO), online: <<http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-aceddo.pdf>> (LCO Report 2014).

email invitation that was disseminated to hospitals, LTC homes, hospices, LHINs, other health organizations (both professional organizations as well as practice groups (such as Health Links)), and patient and disability rights organizations and requested existing HCC, ACP or GOC tools, or those in development. To systematically review the tools, a screening survey was developed based on the existing law. Each tool was then assessed with the screening survey, to determine whether key elements were present, defined appropriately, and where applicable, legally correct.

To explore implementation and effectiveness of various HCC, ACP and GOC tools in Ontario, both targeted interviews and focus groups were conducted. Four semi-structured interviews were conducted with health practitioners, bioethicists, and health care researchers. An interview guide was developed to structure the conversation. Questions focused on exploring the need for tools to support HCC, ACP, or GOC conversations, the process of developing tools, and the use of tools in practice. Interviews were recorded and transcribed.

Five focus group sessions were conducted with different stakeholder populations. The first group focused on stakeholders impacted or targeted by existing HCC, ACP, or GOC initiatives. This included advocacy organizations such as Rainbow Health Ontario, Older Women's Network, Dis-Abled Women's Network, Dying with Dignity, Family Council Association, Patient's Canada, and the United Senior Citizens of Ontario. The second group focused on health law lawyers. The third focused on health care providers, including family physicians. The fourth focus group focused on individuals living with chronic health conditions, their caregivers and support providers. The fifth group focused on legislators. Discussions explored diverse perspectives on the meaning of HCC, ACP and GOC, knowledge of existing initiatives and practice tools, experience with using any practice tools, as well as opportunities for improvements or recommended changes. Two law students⁹⁰ observed the focus groups and took detailed notes, which were synthesized to provide comprehensive summaries of each focus group.

To explore the implementation of existing practice tools in Ontario, as well as the legal implications and impacts of implementing these tools, a literature review of case law and academic articles was conducted. These primary source materials were obtained electronically through government websites and legal databases (e.g., Quicklaw and Westlaw). Secondary source information was obtained electronically through the aforementioned sites and those of

⁹⁰ The authors would like to thank Candice Camilleri and Nareh Ghalustians, who were placed at ACE and DDO as part of Osgoode Hall Law School's Summer Internship Program through the John Plater/James Kreppner Health Law Internship. We also thank ACE summer law student Ruchi Punjabi for her research assistance.

non-governmental organizations.

IV. FINDINGS

A. Tool Assessment

A total of 100 tools were reviewed and assessed using the screening survey. Of these, 43 had a focus on HCC, 43 had a focus on ACP, and 9 had a focus on GOC, while 18 tools had overlapping foci on two or more areas. There were an additional 23 tools identified with an “other” focus, which included topics such as decision-making, CPR, and SDMs.

Table 1 provides a summary of the type of tools for each of the 3 key focus areas.

Type of Tool	HCC (43)	ACP (43)	GOC (9)
Policy and/or Procedure	18	11	1
PowerPoint Presentation	1	2	1
Discussion Guide	1	4	0
Standard Form	10	5	3
Pathway/Algorithm	0	2	0
Brochure	6	10	2
Guideline	2	2	0
Toolkit	3	3	0
Other	2	4	2

Table 2 provides a summary of the target audience identified for each tool

Table 2. Target Audience			
Target Audience	HCC (43)	ACP (43)	GOC (9)
Health Practitioner	28	29	7
Patient/resident	15	20	2
Family/caregiver	3	5	0
Administrator	18	16	2
Other	3	1	0

HCC Tools: Of the 43 tools identified with a focus on HCC, less than half (49%) outlined the correct process for informed consent for treatment, and only two thirds (67%) clearly identified that the person must be capable to make a health care decision. Only some of the tools (44%) explained how to determine if a person is capable, and few (26%) correctly stated that the proposing provider is responsible for assessing a person's mental capacity. Just over a third (37%) of the tools outline consent to a plan of treatment. Two thirds of these tools explained who the SDM is (67%) and outlined the role of the SDM (65%), but less than half indicated that all people have an automatic SDM (45%), more than a third provided the correct hierarchy of SDMs (40%), and less than one third listed the requirements to be an SDM (30%).

ACP Tools: Of the 43 tools identified with a focus on ACP, less than half (49%) provided a definition of ACP aligned with Ontario's legal landscape, and less than half (44%) correctly contextualized ACP in relation to HCC. While almost two thirds (65%) clearly identified that the person must be capable to make a decision, less than a one quarter (23%) outlined the correct process for informed consent to treatment, and even fewer explained how to determine if a person is capable (19%) or indicated that the proposing provider is responsible for assessing if a person is mentally capable (9%). More than one third (35%) of the tools discuss specific treatment options, such that treatment decisions are framed as the intended outcome.

Similar to the HCC tools, over two thirds of the ACP tools explained who the SDM is (68%) and outlined the role of the SDM (65%), but just over one third indicated that all people have an automatic SDM (35%), or listed the requirements to be an SDM (31%), whereas less than one third of the tools provided the correct hierarchy of SDMs (24%). While almost two thirds (63%)

of the tools indicated that wishes must be expressed by the mentally capable patient, only one third (31%) of the tools correctly outlined how wishes can be expressed (orally, written, on video, etc.), and more than half (56%) indicated that documentation of wishes was required. Only about half (55%) correctly explained when to apply wishes, while fewer tools correctly identified who takes directions from expressed wishes (37%), or how to apply expressed wishes (21%). Very few tools outlined what to do if a wish cannot be applied (9%), defined the circumstances for departing from expressed wishes (9%), or defined the term “best interest” (12%).

GOC Tools: Of the 9 tools identified with a focus on GOC, about half (56%) provided a definition of GOC, but all of these were identified as having errors and none of the tools discussed the relation to HCC. Several tools used problematic language, including use of the terms “advance directive” (44%), and “living will” (44%). More than half (56%) of the tools placed an emphasis on specific treatment options and framed treatment decisions as the intended outcome. For example, one tool focused on making a decision about Cardiopulmonary Resuscitation (CPR), while another focused on various life sustaining measures. Importantly, none of the tools clarified that GOC discussions were separate from HCC, and none of these reinforced the importance of obtaining informed consent in the context of health care decision making.

Packages of Tools: Some health care organizations submitted packages of tools. For example, some policies were accompanied by pathways/algorithms or forms, or discussion guides also included forms. It was observed that materials belonging to the same set were often contradictory, with correct information appearing in one, and errors noted in another. Additionally, packages that were developed for use nationally were noted to either be too generic, or too specific. Those that took a broader approach tended to miss the nuances defined in the Ontario law. At the opposite end of the spectrum, one package contained details for multiple provinces, placing the onus on the provider to identify the Ontario-specific content.

B. Focus Groups and Interviews

Qualitative analysis was used to better understand the meaning and content of the data obtained during the focus groups and interviews. To begin the analysis, transcripts for the interviews, along with the summary notes from the focus groups were all thoroughly reviewed to achieve familiarity with the data. Codes were generated to systematically organize the data, and then collated to identify emerging themes.

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interviews and summary notes from the focus groups were thoroughly reviewed to achieve familiarity with the data. Codes were generated to systematically organize the data, and then collated to identify emerging themes.

Discussions revealed that knowledge and understanding of HCC, ACP and GOC was variable among stakeholder groups. Many of the comments reflected a lack of awareness among the general public around these concepts, and how they are related. For example, one participant indicated, “out of the 400+ members; no one knows anything about [ACP or GOC], including teachers, steelworkers”. Another reflected that it “seems like ACP and informed consent are melded together, but each term can be interpreted in different ways”.

A lack of available information, and difficulty accessing information were consistent themes that emerged as factors that impact knowledge of HCC, ACP and GOC. Availability related to whether tools or information could be obtained. Participants acknowledged turning to other jurisdictions to meet their information needs in the absence of Ontario-specific material. For example, one participant pointed out that there is not a “one stop package, so people try to do their own thing, and do not have extensive discussions because of it”. Another participant commented that he “found that the American Bar Association tools online were somewhat useful. If there are tools out there, it may be that they are not doing a good job of making it known”.

In contrast, accessibility related to the extent to which available tools or materials could be used, or provide benefits. Language, the role of health literacy, and culture all emerged as factors that restrict access to materials, impacting knowledge and understanding of these concepts. For example, one participant explained that HCC, ACP and GOC are “very much health professionals jargon, and in most cases it ends up being confusing for the lay person that is trying to navigate the system and plan for their future care”, further cautioning that there is a “need to be careful with use of terms and processes”. Another participant noted how “talking about values and beliefs makes it sound intellectual. It is really about how people want to live their lives”. Importantly, it was called out that “The concept of literacy trumps everything, so we need to be clear about definitions and avoiding silos”. Finally, the influence of culture on understanding was well captured by a participant who stated “depending on who you are and your level of understanding of health care and geographical differences, you may have a different understanding of each. This is a problem, this is a result of different cultures.”

Health practitioners were perceived as having a basic knowledge of HCC, ACP and GOC, but not always recognizing the distinction between these concepts. For example, one of the researchers observed “the way people conceive of it mentally or conceptually in their minds

has been a lot different than the way that we are trying to break it out into distinct things. It's a complex thing to get across." In particular, health practitioners were perceived as lacking an understanding of the intersections between HCC and ACP as well as GOC, and how these connect to the laws in Ontario. One lawyer commented that "providers are unlikely to get the consent part right... they do not understand who gives consent and who is responsible for getting it". Another stated: "most physicians do not have a clue about what the law states about their legal requirements... They just think they are obliged to provide the best care possible rather than obtaining informed consent."

The observation that knowledge of these concepts did not always translate into practice was a consistent theme. One stakeholder explained "the limitations of ACP are important, and understanding how you interpret them at the bedside for specific medical decisions is not always easy". A common misinterpretation of ACP identified by several stakeholders was the conflation of ACP with consent. One of the health practitioners observed how "even people who are engaged in it kind of view ACP discussions as equivalent to getting a DNR". Similar issues were also identified with the application of wishes. For example, one stakeholder remarked that health practitioners "do not pay attention to validity. If something is written in a POA, it is assumed the wish is consent. If you have written it down, they never go to the substitute [decision-maker]".

Another stakeholder explained:

From the clinician's perspective, ultimately what we need to know is if this person starts to deteriorate really quickly in a crisis, how much are we going to do? Especially the nurses in a hospital setting feel that way. If I walk in on my patient and they are gasping for air, am I supposed to call the code or not? For practical reasons, I think we get hung up on the treatment decisions.

Preoccupation with treatment-centered discussions was a repeating theme, with one health practitioner sharing: "we tend to start with [asking about CPR] with patients and families because we are really focused on getting the code status or whatever else we want, such as the specific treatment, addressed". However, as another stakeholder cautioned, "the purpose of [ACP] is not aimed at getting a DNR order or a document with specific medical orders on it that are rarely all that helpful". They went on to correctly identify that instead, these conversations require health practitioners to "participate in an exploration of values but also explain what kinds of scenarios may come up, and prepare [the SDM] for making in-the-moment decisions". Stakeholders consistently identified health practitioner discomfort with discussing HCC, ACP, and GOC, and suggested various contributing factors. For example, one of the health

practitioners shared “We tend to be uncomfortable with those discussions or don’t have the skills training that we would ideally want to have to guide those conversations”. The lack of training was a common thread, with one health practitioner indicating that routine feedback received from residents was “that they don’t get any training in this area, and that they often get thrown into the room to have these conversations short on context, training, supervision and feedback, which is very sub-optimal”.

Another health practitioner commented on the “need to break down old habits” and the challenge of “getting health care practitioners to know what they don’t know”. Importantly, this same health practitioner affirmed that “many of them are willing to do the training but the policies and forms at their institutions drive incorrect behavior regarding who to talk to and when”. A key concern linked with a lack of training, was highlighted by another stakeholder who explained “you can prepare patients and families till you’re blue in the face, but if there’s no clinician ready to receive that prepared patient or family, and have that discussion, then all the effort to do the preparation is not going to get you that far”.

A tendency for health practitioners to be “conflict averse”, was also identified as a common factor impacting discussions. One health practitioner expressed that when faced with difficult conversations, “we knuckle under. This isn’t the problem with the law. This is the problem with how we make decisions. We don’t want to go against families or be in conflict”. The role emotions play in shaping conversation outcomes is also well-illustrated in this quote:

If the physician and the patient are already on the same page and have already come to the same conclusion, then that can be a very easy conversation. The challenge and the reason why we don’t end up doing this so often, or why we get afraid of these conversations, is because sometimes that doesn’t happen. Sometimes you get people with quite substantially different or unrealistic expectations of what’s going to happen, or people get very upset.

Discussions around the legal aspects of HCC, ACP and GOC highlighted an interesting dichotomy. Several stakeholders agreed that health practitioners’ actions were often motivated by legal implications. One individual remarked “there is a lot of fear that if they do not provide care/intervention the family will sue, even if in reality the resident wants to be left alone and does not want the interventions”. Similarly, another stakeholder commented that “practitioners feel strongly about complying with patient wishes, even if they are not relevant to the situation, because they worry about liability”. In contrast, despite a recognized fear of litigation, many stakeholders acknowledged a lack of legal repercussions for health practitioners. As one stakeholder observed, “there is a lack of enforcement mechanisms and recourse under the HCCA”. Another individual jokingly pointed out that “If the Health Care Consent Act was actually enforced, how big would the Public Guardian and Trustee office need

to be?” Not surprisingly, stakeholders also viewed this as impacting health practitioners’ actions, as one individual specified, “we have a law that is well-defined, but there is non-compliance in practice”.

A failure to comply with patient’s express wishes, values and beliefs is especially concerning given stakeholders perception that patients have limited agency with respect to their treatment. For example, one lawyer expressed “the patient cannot make complaints about quality of treatment, and must oblige with the status quo in order to be able to get the treatment. It is hard to exercise choice and make complaints about how care is being delivered in times of crises.” Another stakeholder commented “Because of the vulnerable position a patient is in and the threat they face in not getting treated at all, there is essentially nothing much they can do to object to the way they are being treated.” Complicating matters further, stakeholders also emphasized the influence of paternalistic health practitioners on health care, as well as treatment decisions. For example, one of the lawyers felt that “the vast majority of people that are incapable are being treated without consent. They just get treated because they need treatment and providers think they know what is right”.

Another stakeholder suggested that families avoid having ACP conversations, and “leave it to the physician to put the right thing on the table” when faced with making a treatment decision on behalf of the incapable patient. This individual underscored how without these conversations, “you don’t have wise, thoughtful reflective decisions made about [the incapable patient] that will be appropriate”, but rather end up with “the most aggressive default pathway”. Even more telling, this stakeholder concluded “people dying in ICU and people dying getting CPR is rarely the result of a planned process – a decision that was reflecting medical reality and [the patient’s] wishes. It’s almost always the result of a failure to do that”.

V. DISCUSSION

The review of practice tools for this research paper as well as the experience of the writers from their own work is that many practice tools in use do not appropriately reflect all elements of the Ontario law on HCC and ACP. Importantly, many of these tools do not support health practitioners in getting an informed consent as defined in the HCCA. The same can be said about many of the ACP and GOC tools for health practitioners that too often do not show the connection to HCC or, more concerning, fail to clarify that these tools cannot be used as consent to treatment. For the most part, practice tools do not inform the patient or those who will act as their SDMs that consent is required before treatment. Similarly, very few tools explain to the patient or their SDM what their rights and responsibilities in these processes are.

Significantly, many documents contain legal errors, and as result, perpetuate misperceptions and misunderstandings of these distinct processes.

It would be easy to conclude that a set of standardized tools mandated for use in all forms of health delivery would be the solution to this problem. However, that may be too simplistic a conclusion as the health system is very complex, and the needs of the different users (health practitioners in different types of health settings, patients, SDMs for patients, other health services providers) are variable.

There are many challenges to creating a common set of practice tools for HCC, ACP and GOC that would be considered “acceptable” in all parts of the health system. There would also be challenges in operationalizing a common set of practice tools across all types of health settings. The following discussion of these challenges is based both on the research done for this project, but also from the experience of the writers in their day to day work in health policy and health law from the legal, health care organization, health practitioner, patient and family caregiver perspectives.

A. Missing the Connections between HCC, ACP and GOC

It is clear from both our research findings and our collective experience that there are fundamental misunderstandings across the Ontario health system about basic elements of informed consent and ACP, and specifically, the intersection of HCC, ACP and GOC. Unless this interconnection is understood, it is unlikely that existing tools will be used appropriately; or that flaws in existing tools will be identified or understood. This lack of understanding of the interconnections among these concepts also hampers the development of better tools to support consent, ACP and GOC discussions while properly reflecting the Ontario legal framework.

HCC and ACP are interconnected processes. Person-focused GOC discussions are a step in the informed consent process. In Ontario, much emphasis is placed on ACP and “wishes” rather than on the elements necessary to obtain an informed consent. Little attention is focused on how ACP connects to HCC. GOC may be treated as ACP by some health practitioners and as consent by others when in fact GOC should be neither, as stated above.

The intersection between these concepts may be explained by reviewing the various roles and responsibilities of the health practitioner, the patient and the patient's SDM. First, health practitioners are required to get an informed consent to a treatment before providing that treatment. As stated above, they must get that consent from the capable patient or the

incapable patient's SDM. The health practitioner must ensure that the patient has a good understanding of their health condition and the options for treatment. In explaining treatment options, the health practitioner must provide the necessary information to the patient or the incapable patient's SDM to meet the standard for an informed consent.

Our research findings suggest that health practitioners may not fully understand the requirement for informed consent. For example, a physician expressed to one of the writers that clinicians generally understand that consent is necessary for surgery but not for all treatments. Equally concerning, many health practitioners seem to conflate ACP with consent, such that any discussions with patients about treatment taking place in the future, are considered ACP. For example, several stakeholders spoke about ACP conversations focusing on code status, or CPR. Care or treatment decisions, whether in the current context, or in the future context, are the outcome of health care consent, and namely, treatment discussions, not ACP. A patient may consent to a plan of treatment that includes consent to specific current treatments as well as deals 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 “provide(s) for the withholding or withdrawal of treatment in light of the person’s current health condition”.⁹¹ This is another example of what may be a failure of health practitioners to understand informed consent; only a few seem to understand how a “plan of treatment” may be used, with consent of either the capable patient, or if incapable, the patient’s SDM.

To obtain consent, the health practitioner must talk to the patient (or the incapable patient’s SDM), rather than taking directions from a document or any other form of ACP wishes. If the health practitioner is aware of the patient’s previously expressed wishes, values, and beliefs, the health practitioner may want to discuss these with the patient. However, the previous wishes should not be used to limit the treatment options discussed. The patient may have a different perspective at the time consent is to be provided once they better understand their present condition and the available treatment options arising from that condition.

If a patient is incapable, the health practitioner does not take direction from previously expressed wishes, such as a POAPC. Instead, the practitioner must discuss treatment options and obtain consent (or refusal) from the SDM. That discussion may review whether the wishes were the last capable wishes of the patient, whether the patient changed these either orally or

⁹¹ Under the HCCA, a “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. See HCCA, *supra* note 1, s. 2(1).

in writing or by any other means and whether the wishes are applicable to the present treatment decisions that need to be made. The health practitioner has an obligation to explain to the SDM that the SDM is required to make decisions for the patient by following the last capable wishes of the patient that are applicable to the treatment decision to be made.⁹²

When talking with the incapable patient's SDM, it is important that the health practitioner first inform the SDM about the patient's health condition before asking the SDM what "wishes" the patient may have expressed about their future care. The SDM needs to understand the patient's condition to then determine if the patient previously expressed wishes that are applicable to the decision that the SDM must now make. The order of the discussion is important. The SDM must first have the context in order to apply the patient's prior capable wishes to the decision at hand.⁹³

Although the health practitioner's primary role under the law is to engage in discussions to obtain an informed consent, they are encouraged to engage in ACP with patients because of the identified benefits for patients, their families, and the health system. In the *Clinician Primer-ACP Conversation Guide*, Dr. Nadia Incardona and Dr. Jeff Myers summarize research that evaluates the impacts of health practitioners engaging in ACP with their patients. The evidence suggests that ACP and consent improve patient and family satisfaction with end-of-life care;⁹⁴ decrease caregiver distress and trauma⁹⁵ decrease unwanted investigations, interventions & treatments;⁹⁶ increase the likelihood of dying in preferred settings;⁹⁷ decrease hospitalizations and admissions to critical care⁹⁸; and decrease cost to the health care system.⁹⁹

Next, we turn to patients and their SDMs. Patients while capable may engage in ACP conversations. First, the patient should determine their future SDM, either by confirming

⁹² *M. A. v. Benes*, 1999 CanLii 3807 (ON C.A.), (1999), 46 O.R. (3d) 271.

⁹³ HCCA, *supra* note 1, s 42(1). Per s. 22(1) Before giving or refusing consent to a treatment on an incapable person's behalf, an SDM is entitled to receive all the information required for an informed consent as described in s. 11 (2).

⁹⁴ Heyland, DK et al. "Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning" (2013) 173:9 JAMA Intern Med 778.

⁹⁵ Wright, AA et al. "Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment" (2008) 300:14 JAMA 1665.

⁹⁶ Canadian Hospice Palliative Care Association. "Speak Up" (2013), online: <<http://www.advancecareplanning.ca>>.

⁹⁷ *Ibid.*

⁹⁸ Detering, KM, "The impact of advance care planning on end of life care in elderly patients: randomised controlled trial." (2010) BMJ, 340.

⁹⁹ Zhang B, et al. "Health Care Costs in the Last Week of Life Associations with End-of-Life Conversations" (2009) 169(5) Arch Intern Med, 480.

satisfaction of their automatic SDM or by preparing a POAPC to name a particular person (or persons) as their attorney. Second, the patient communicates to their future SDM their wishes about future care, as well as their values and beliefs. Patients may communicate anything they think would help their SDM make health care decisions for them in future once incapable, as close to what the patient would have decided if capable. However, patients cannot “pre-consent” to future treatments. Wishes are not consents. To provide an informed consent the patient must have the information of their present condition and their current treatment options.

The goal of ACP is to prepare the person who will act as the patient’s future SDM to make substitute decisions for the patient when incapable. This is a very challenging role. Without this communication through an ACP process, the SDM would be placed in a difficult position, trying to guess what the patient would have wanted if still capable to decide. ACP conversations help the SDM to understand what is important to the patient. The patient may not be able to indicate preferences for a particular treatment because those types of wishes are speculative, and are expressed without any context. However, the patient may be able to communicate what they think is important to them, what they consider to be quality of life, and what they value about their life and their health. These wishes, along with the patient's values and beliefs, should help guide the SDM and give them confidence to make health care decisions that reflect the patient.

Only patients while capable may do any part of advance care planning for themselves.

For example, only patients while capable may name an attorney for personal care by executing a POAPC. A family member or friend of the patient cannot sign the POAPC on their behalf. If a family member or friend has reason to believe that the incapable patient would not have wanted the previously named attorney for personal care or the automatic SDM to act, they can apply to the Superior Court to be appointed as the patient’s Guardian of the Person. If there was no pre-existing POAPC, another option is to make an application to the Consent and Capacity Board to be appointed as the patient's representative.¹⁰⁰

Several practice tools reviewed as part of this research paper purport to give authority to SDMs to express “wishes” for the incapable patient. To reiterate, only patients while capable may express “wishes” for their future care or express their values and beliefs that influence how they think about health decisions. In contrast, the role of the SDM is limited to giving or refusing consent to treatment on behalf of the patient who is incapable for a treatment

¹⁰⁰ HCCA, *supra* note 1 at s. 33.

decision; this could include an SDM providing consent to a plan of treatment under the HCCA as described earlier in this research paper.

The SDM must be given information about the incapable patient's health condition and treatment options prior to making an informed decision. The SDM must consider which of the wishes expressed by the patient, when capable, apply to the particular treatment decision, and are possible to follow. If no wishes are known, then the SDM must make decisions for the patient in his or her best interests considering their values and beliefs. SDMs cannot express ACP "wishes" for the incapable patient. Furthermore, when an SDM provides direction about DNR/No CPR for a patient, the SDM is not engaging in ACP. Instead, the SDM is providing consent to a treatment (or no treatment) or to a plan of treatment that will take place at a future time.

This distinction between the roles of the patient and the SDM in ACP has caused some confusion for health practitioners. Health practitioners, particularly family practitioners, are being encouraged to engage in ACP with patients. ACP wishes are primarily information that the future SDM needs to know and understand to be able to make decisions for the patient if and when the patient is found incapable to consent to a particular treatment. Optimally, the ACP process involves the patient and his or her future SDM participating in the patient's ACP discussions with the health practitioner. However, many patients do not attend medical appointments with their future SDMs. That is neither practical nor appropriate in all circumstances. Further, health practitioners should be aware of privacy requirements in the *Personal Health Information Protection Act, 2004*¹⁰¹ (PHIPA) that would require them to get consent of a patient to discuss the patient's health condition and treatment options with another person, even if that person is the patient's future SDM.

Health practitioners need to think about the different components of the ACP process. All health practitioners should include information about the patient's future SDM(s) in the patient's health record, recognizing that the patient could in future choose a different SDM, or someone in the hierarchy may not meet the legal criteria to assume the role (including the requirement to be willing, available and capable). The HCCA hierarchy and specifically the name and contact information for the patient's SDM are important elements to include. Discussions about a patient's future SDM, including their roles and responsibility, and determining who that person may be, can be done with a patient alone, without their future SDM being present.

Similarly, health practitioners can explain to patients about informed consent, that they would need to turn to the patient's SDM for consent should the patient become incapable, and that

¹⁰¹ *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A (PHIPA).

the patient may engage in ACP conversations to prepare their future SDM for this role. Discussions about these topics would not need the patient's future SDM to be present. However, if a patient indicates they want to discuss ACP wishes with the health practitioner, or if the health practitioner determines it is important to discuss these with the patient, the health practitioner can propose including the future SDM in this conversation. This addresses any concerns about privacy as well as structures the discussion to ensure all the appropriate players are present.

B. Limited Education on HCC, ACP and GOC

One of the prominent themes identified in both our interviews and focus groups was a lack of education amongst health practitioners around HCC, ACP and GOC. In particular, communication skills were acknowledged as a noticeable gap in training.

For a sample of the education programs, inquiries were made to representatives of both undergraduate and post-graduate medical training programs at medical schools at McMaster, University of Western Ontario, University of Toronto and Northern Ontario School of Medicine to obtain information about curriculum content on informed consent and advance care planning. Not all sites responded. The most comprehensive response was sent by a Postgraduate Medical Education & Continuing Professional Development Office.

The responses received varied. Three university representatives advised that consent issues may arise in some courses, particularly those dedicated to research, but these would be limited to discussions about obtaining consent to participate in a research study. There was no specific training on the legal requirement to obtain informed consent prior to treatment in the undergraduate program. One interviewee stated that undergraduate medical education focuses on “current issues and gaps”. She explained that education on consent is not built into the curriculum because “physicians do not deem consent to be an issue.”¹⁰² She went on to say that requirements for consent would be embedded into simulations.

More than one university undergraduate program treated consent and ACP as more appropriate to ethics programs, not core medical education. Even under ethics, the amount of education was limited. One university has a two-hour ethics session about consent with paediatric patients and another two-hour session involving education by physicians, ethicists and lawyers on consent generally.

¹⁰² Email response from University representative (not attributed to particular person to maintain confidentiality)

Consent issues may arise in other courses including one on transition to clerkship and another on transition to residency. In clerkship training, one university includes targeted courses on consent for surgery and in paediatrics, but does not focus more broadly on consent as a general and necessary requirement for all treatment. One interviewee guessed that the total amount of time devoted to consent issues in all courses in undergraduate training would likely be six to eight hours overall. More than one person interviewed commented that this training should take place when the medical students have graduated and are in their “place of employment”.

The response from the Postgraduate Medical Education and Continuing Education Office of one university stated that:

Informed consent or consent to treatment is included in the curriculum framework of the Canadian Medical Education Directives for Specialists (CanMEDS). CanMEDS is a framework for improving patient care by enhancing physician training. It was developed by the Royal College of Physicians and Surgeons of Canada, and its purpose is to define the necessary competencies for all areas of medical practice and provide a comprehensive foundation for medical education and practice in Canada.¹⁰³

We were advised that the competencies are grouped thematically under seven roles, namely:

1. Medical Expert
2. Communicator
3. Collaborator
4. Leader
5. Health Advocate
6. Scholar
7. Professional

The CanMEDS-FM competencies were adopted by the College of Family Physicians of Canada and are now included in the CFPC Triple C Curriculum in the Medical Expert role of the RCPSC CanMEDS framework.¹⁰⁴

One of the competencies under Medical Expert Role is to “plan and perform procedures and therapies for the purpose of assessment and/or management.” The enabling competency is to “Obtain and document informed consent, explaining the risks and benefits of, and the rationale

¹⁰³ Email response from Vice Dean of Postgraduate Medical Education and Continuing Education Office.

¹⁰⁴ <http://www.royalcollege.ca/rcsite/canmeds/canmeds-framework-e>.

for, a proposed procedure or therapy.”¹⁰⁵ Another key competency is to “perform a patient-centred clinical assessment and establish a management plan.”¹⁰⁶ The enabling competencies for that include establishing “goals of care in collaboration with patients and their families, which may include slowing disease progression, treating symptoms, achieving cure, improving function, and palliation” as well as “a patient-centred management plan.”

There is also an online course at the University of Toronto that is a mandatory for 1st and 2nd year Residents in Postgraduate Medicine and is available for other Residents and Fellows. An interviewee advised that the "End of Life Care" course discusses the ethical and legal requirements of capacity, consent and decision-making as well as SDMs. All residents must complete this module in order to proceed to their 3rd year of residency (for specialty programs) or to write the CFPC certification exams (Family Medicine).

We were also advised that during clinical training, residents must perform under the supervision of the Most Responsible Physician (MRP) as outlined in the College of Physicians and Surgeons of Ontario's policy on Professional Responsibilities in Postgraduate Medical Education. Both the MRP and the medical resident should follow the CPSO's Consent to Treatment policy.

The CanMEDS competencies include reference to the legal requirement for an informed consent. It is laudable that the Royal College of Physicians and Surgeons has identified this as part of core competencies for physicians. It is also important that the requirement for informed consent is included in undergraduate medical education. However, the details of this education are unclear. Medical schools appear to limit the importance of consent, teaching it as fundamental only to research and surgery, framing it as an “ethical” issue that must be considered by physicians. However, the details about consent are necessary in all forms of medical care and are part of the legal requirements, not just ethical decision making. Whether the education on consent is sufficiently detailed or legally correct is a question that requires more investigation.

We were given an excel spreadsheet of a postgraduate program on consent at one medical school that outlined expected physician learning outcomes following the course. These include the following:

“Define how to obtain consent by explaining that the consenting patient must have the legal capacity to consent (i.e. be of legal age) and be competent to do so...”

¹⁰⁵ <http://www.royalcollege.ca/rcsite/canmeds/framework/canmeds-role-medical-expert-e>.

¹⁰⁶ <http://www.royalcollege.ca/rcsite/canmeds/framework/canmeds-role-medical-expert-e>.

“Recognize that if the patient is not competent to do so a parent or court appointed guardian or other SDM may provide the consent.”

“Demonstrate a working knowledge of the provincial health acts (such as the Mental Health Act and the Consent and Capacity Act).”

There are a number of concerns related to these statements. To begin, it is unclear whether this program focuses on operationalizing consent in Ontario, or is more generic, since physicians may end up practicing medicine in other jurisdictions. If it is Ontario-specific, it does not make clear that there is no age of consent in the HCCA; i.e., capacity to consent is based on a legal test, rather than age. If it is more generic, then the physician should be able to demonstrate that he or she understands that the law in the jurisdiction in which they practice may set different criteria that affects when a person may give or refuse consent.

The second statement is correct in that if the patient is incapable for treatment then consent must be obtained from an SDM. However, the learning outcome should be focused on determining the decision-maker under the law of the jurisdiction in which the physician is practicing.

The third statement refers to legislation that does not exist in any province (“The Consent and Capacity Act”).

More attention needs to be paid to the details on informed consent as it is basic learning that all physicians and other health practitioners need to acquire to provide patient-centred care, to comply with the law and to protect themselves and their workplaces from any civil liability or professional misconduct.

C. No One Voice of “Authority” and No One “Regulatory Body”

Using the word “regulatory” in its broadest sense of requirement for accountability, there is no one voice of “authority” and no one “regulatory body”, to which all health practitioners and all health care organizations account to or turn to as a resource. By making this statement, this is not to suggest that there should be one regulatory or governing body or one voice of authority. It is merely a statement of fact.

Health practitioners and health care organizations and all other actors within the health system must report or account to a variety of players. There may be different expectations amongst all the different authorities as to what the priorities are or what is significant to the health practice or health service. Although adherence to the HCC and ACP legal framework may be acknowledged as being a central element to “person-centred care”, there are also pressures in

the health system to deliver health care faster, cheaper, and more efficiently. How that is defined may limit or in some circumstances prevent the ability of health practitioners to adhere to the best HCC and ACP processes. Some of the key factors include time, availability of staff, and pressures to move people through the system (right care, at the right time in the right place).

D. Mixed Messages

Health practitioners receive varied messages from the many authorities they interact with. Further, messaging within a given authority is sometimes inconsistent. Despite the excellent work of many health sector organizations, health practitioners and others on the frontline occasionally receive mixed messages about what is a good practice in respect to HCC, ACP and GOC. Some examples include:

1. Health Quality Ontario (HQO)

As part of its Residents First: Advancing Quality of Long -Term Care Homes Initiative, HQO has published a document called *Quality Improvement Road Map to Emergency Department Utilization*.¹⁰⁷ It includes the following statement as a possible area of focus for “Care Planning for Prevention”:

An individualized plan of care is created with the resident, family and staff and is based on best practice evidence, and assessed risk while considering first the residents’ values, beliefs, and preferences.¹⁰⁸

This is a generalized statement of good practice, but it does not go an important step further. It cannot be directly implemented without first translating it into the context of the HCCA, the LTCHA and other relevant health legislation.

As previously noted, the legal requirements outline that a plan of care must be developed with the appropriate decision-maker – whether the patient if capable or if incapable, the patient's SDM. The patient or SDM may choose to have other family involved with development of the plan of treatment. Health practitioners cannot include “family and staff” if the patient is capable unless the patient provides consent (or based on implied consent if the staff are part of the circle of care). This is required under PHIPA.

¹⁰⁷ Health Quality Ontario, “Quality Improvement Road Map to Emergency Department Utilization”, online: <<http://www.hqontario.ca/portals/0/Documents/qi/rf-change-package-emergency-dept-util-en.pdf>>.

¹⁰⁸ *Ibid.*, p. 11.

The patient's values, beliefs and preferences are part of the discussion with the patient or SDM. However, the patient or SDM must first have an understanding of the patient's current condition so that they have the current context within which to apply their values and beliefs, and about which they can express preferences. Understanding context is critical for the patient and their SDM. If the context changes, a patient's previously expressed wishes may no longer be relevant.

This document also includes the following statement as a "suggested step" for "Care Planning for Prevention": "Understanding Advance Care Directives that impact ED utilization."¹⁰⁹ Although commonly used, Ontario law does not have any term or provide for documents called "advance directives". For example, assuming HQO is directing health practitioners to consider a LTC resident's decisions or "wishes" expressed when capable about not wanting to transfer to hospital from the LTC home in which they then reside, the health practitioners must turn their attention to how to operationalize this. Specifically, the health practitioner would need to consider whether the wish for "no transfer" is applicable at the time transfer to the emergency department is being considered (and what was behind the "no transfer" wish). This may involve conferring with the patient again in the context of the present circumstance, or if the resident is incapable, with their SDM. The health practitioner should also determine if the patient has made an informed decision (as opposed to a wish) about "no transfer".

The ACE and DDO experience is that some LTC home residents who know they are at end-of-life decide they do not want a transfer to hospital, even in an emergency, preferring to forgo emergency treatment in favour of receiving care at the LTC home. Despite this decision, a resident may still want to transfer to the emergency department if they fall and break a hip or if they need short-term care at a hospital for a treatable condition that helps them remain comfortable upon return to the LTC home. The risk in a home relying on the broad "no transfer" means that it is sometimes applied to all circumstances, even where the resident really meant it in the case of end-of-life.

HQO's report outlines several appropriate principles including the need for direct communication with the residents, and whomever else they wish to be part of the discussions; the need to have an appropriate plan of care; and ensuring that the plan of care reflects the resident's values, beliefs and preferences. These statements are general in their application and a good start; however, the next step must be to optimize their operationalization, in keeping with the requirement for informed consent. Otherwise, the statements may run the risk of conflating ACP with health care decision-making.

¹⁰⁹ *Ibid.*

HQO is an influential entity in the health system and it is likely that health practitioners and management of health care organizations and health practitioners will seek advice and take direction from what is on the HQO website. We do note that in a report on Palliative Care just released by HQO, HQO includes a statement about what is ACP, citing the Advance Care Planning Quick Guide Ontario Edition from HPCO.¹¹⁰ This statement very ably sets out what ACP is in Ontario. It also confirms that:

.. health care providers are required to get informed consent before giving you any treatment or care. That consent must come from you, if you are mentally capable of doing so. If not, consent must come from your substitute decision maker.¹¹¹

That Guide and the HQO report on Palliative Care both clearly and correctly state that there are no such documents as “advance directives” in Ontario. Consistency in terminology specific to Ontario will only serve to reduce fundamental misunderstandings about HCC and ACP.

2. Canadian Institute for Health Information (CIHI)

CIHI is a national organization with the mandate to “deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care”.¹¹² In its PowerPoint Executive Summary of the report, *How Canada Compares: Results From The Commonwealth Fund 2014 International Health Policy Survey of Older Adults*¹¹³, a slide with data from CIHI’s “Continuing Care Reporting System, 2011” reports that advance directives are common in LTC. We note, as above, that “advance directives” are likely better described as informed decisions about treatments as they typically consist of DNR orders, feeding restrictions, and medication restrictions. Reframing the language in this more general way would allow for broader use, including Ontario, where the term “advance directive” does not apply.

¹¹⁰ Canadian Hospice Palliative Care Association. “Advance Care Planning Quick Guide”, online: SpeakUp Campaign <http://www.advancecareplanning.ca/wp-content/uploads/2015/09/ACP-Ontario-Quick-Guide-03.2015_colour_FINAL-web.pdf>.

¹¹¹ Health Quality Ontario. “Palliative Care at the End of Life” p. 38, online: Advance Care Planning in Ontario. <<http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf>>.

¹¹² Canadian Institute for Health Information (CIHI). “CIHI’s Strategic Plan, 2016 to 2021” p.12, online: CIHI <<https://www.cihi.ca/en/strategicplan2016-2021-enweb.pdf>>.

¹¹³ Canadian Institute for Health Research and Canadian Institute for Health Information. “How Canada Compares: Results from the Commonwealth Fund 2014 International Health Policy Survey of Older Adults” (January 2015), online: Commonwealth Fund 2014 <<https://www.cihi.ca/en/health-system-performance/performance-reporting/international/commonwealth-fund-survey-2014>>.

CIHI collects this data from the Resident Assessment Instrument - Minimum Data Set (RAI-MDS) Canadian Version forms. However, the two boxes on the forms that refer to the health decision-maker (Box A9 Responsibility/Legal Guardian) and end-of-life treatment decisions (Box A10 Advance Directives) do not reflect Ontario legislation. As CIHI is collecting data across Canada, it is understandable that the forms used cannot reflect all the differences in provincial law. However, in our view, these two boxes on the RAI-MDS do not precisely reflect the law in any given Canadian province. The fundamental issue is that the treatments or decisions in this list are not just “wishes” of patients, but would require an informed consent. For that reason, referring to these as “advance directives” is potentially misleading.

Excerpt from RAI-MDS Canadian Version

A9 RESPONSIBILITY/ LEGAL GUARDIAN

- a. Legal guardian
- b. Durable power of attorney/financial
- c. Other legal oversight
- d. Family member responsible
- e. Endurable power of attorney/health care
- f. Resident responsible for self
- g. g. None of the Above

A10 ADVANCED DIRECTIVES

- a. Living will
- b. Do not resuscitate
- c. Do not hospitalize
- d. Organ donation
- e. Autopsy request
- f. Feeding restrictions
- g. Medication restrictions
- h. Other Treatment restrictions
- i. None of the Above

It must be concluded that the data collected from these forms on these matters are not accurate since the terminology used does not reflect the Ontario law. Staff in LTC homes may interpret these sections of the forms in different ways since terms such as “living will” do not have any specific common meaning, despite their entrenched use across the Ontario health sector.

ACE has had direct experience with how these forms contribute to misunderstandings about HCC and ACP. ACE has dealt with many client matters where LTC home staff were insistent that “living wills” were required for all residents because of the inclusion of this term on the RAI-MDS. Similar statements were made about requirements for DNR orders. SDMs who are attorneys in POA for property were also treated as having authority to make treatment decision for the incapable resident because the RAI-MDS form includes that person on the list of decision-makers.

It is our understanding that the Ontario Ministry of Health and Long-Term Care (MOHLTC) requires long-term care homes in Ontario to use the RAI MDS to support assessment and care

planning for residents. The data is also used as “quality indicators” for “evidence based quality improvement initiatives.”¹¹⁴

On June 2, 2016, CIHI released a report *A Snapshot of Advance Directives in Long-Term Care: How Often Is “Do Not” Done?*¹¹⁵ This study is described as examining “how often do-not-hospitalize (DNH) and do-not-resuscitate (DNR) directives were recorded for residents in 982 reporting Canadian LTC facilities between 2009–2010 and 2011–2012 and, to the extent possible, whether these directives were followed in acute care settings.”¹¹⁶ The writers of that report state that “The findings of this study will shed light on how end-of-life preferences of long-term care residents are upheld and communicated across the continuum of care.”¹¹⁷

While welcome, we note that the report is limited in that it only looks at the data collected from the RAI-MDS on the DNR and DNH, but does not look at whether the data was correctly recorded by LTC home staff. It does not examine whether health practitioners engaged in appropriate discussions with patients or their SDMs about the patient's health condition and treatment options that lead to the completion of the forms that created this data. This report does not examine whether or not informed consent was obtained for a DNR or DNH designation.

The writers of this report refer to the statements of DNR and DNH as “directives” when in fact, in many cases, the decisions about DNR in particular would be informed consents considering the age and health condition of the majority of LTC residents. The writers also make statements about when “directives” (which in Ontario would be recorded ACP wishes) would be in effect, stating:

It is important to note that a DNH directive comes into effect only if the resident is unable to provide informed consent at the time of a decision to hospitalize or if a family member or legal guardian is unavailable to consult about treatment options.¹¹⁸

This statement infers that the health practitioner can take direction from a “directive” to not hospitalize a resident if they are incapable; while that belief is widespread in Ontario, it is incorrect. If the resident is incapable, the health practitioners are required to contact the

¹¹⁴ Fougere, Greg. “Long Term Care Quality Indicators and Public Reporting In Ontario: Are We There yet?” (2009) 2;1 *Qmentum Quarterly*, 23.

¹¹⁵ Canadian Institute for Health Information. “A Snapshot of Advance Directives in Long-Term Care: How Often Is ‘Do Not’ Done?”, online: Analysis in Brief (May 2016).
https://secure.cihi.ca/free_products/advance_directive_ofTEN_do_not_done_en.pdf

¹¹⁶ *Ibid*, p. 4.

¹¹⁷ *Ibid*, p. 4.

¹¹⁸ *Ibid*, p. 7.

resident's SDM to discuss treatment options which may require a transfer to another health care organization. In an emergency, the health practitioners could make their own decision as to what to do. Ordinarily, if an SDM is unavailable, the health practitioners are required by the HCCA to turn to the next-highest ranking SDM for a decision. Patients (including residents) always have an SDM because the OPGT is the SDM of last resort under the HCCA hierarchy.

This report states:

While long-term care facilities in Canada typically discuss care goals with residents, little information is currently available to understand what kind of directives are in place, and whether documented patient preferences are being followed in clinical practice and across the continuum of care.¹¹⁹

This statement raises the prospect that documented patient preferences are being relied on absent the required discussion in Ontario with the applicable SDM of the incapable patient. The writers conclude that the report provides good baseline data about the use of DNH and DNR directives in LTC. However, if the "directives" are obtained without appropriate consent (including explanation and discussion) before recording such information on the chart or in the CIHI forms, that is problematic.

This report certainly will and is having a reach; some physicians have already taken the position that this report is scientific evidence of the need for and justification of "level of care" forms that include statements about DNR and DNH. They also argue that health care organizations may take direction from such statements when a patient is not capable, which is not the case other than in an emergency.

To resolve these issues, there should be more generic language in forms used nationally, and for data collection; this should include a focus on how to engage in and present national research that captures provincial variations in law if those differences have impact on the health research.

3. Canadian Medical Association (CMA)

The CMA is a national, voluntary association of physicians and physicians-in-training that describes itself as "the national voice for the highest standards of health and health care". The following are two excerpts from their 2015 Advance Care Planning Policy:

¹¹⁹ *Ibid*, p. 11.

A patient's duly executed advance care plan shall be honoured by the attending physician unless: a) there are reasonable grounds to suppose that it no longer represents the wishes of the patient; or b) that the patient was coerced or lacked capacity at the time the plan was prepared.

...

Patients frequently believe that an advance care plan will be honoured under all circumstances. The reality of medical practice makes this impossible. If the advance care plan is specific to a particular set of circumstances that are not in play when the patient becomes incapable, the plan itself will have no force, although it can provide indications as to the patient's values. On the other hand, if an advance care plan is so general that it applies to all possible circumstances that could arise, it may be too vague to give any usable direction to the physician. In either case physicians will have to rely on their professional clinical judgment to decide if the advance care plan applies to the situation at hand. Physicians and patients can refer to relevant provincial laws on advance care planning.¹²⁰

The policy as illustrated, starts from the premise that advance wishes of a patient must be followed by the physician and it is the physician who decides whether an ACP wish is applicable to the treatment decision. In Ontario, this is squarely the role of the SDM. There is no explanation in this policy as to how ACP wishes relate to the consent process. The sentence referring physicians to their own provincial legislation offers little to highlight the differences between provinces. Further, it does not clarify that these differences can have implications on the role of the physician in advance care planning.

The CMA Code of Ethics further states that physicians should:

Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.¹²¹

When the intentions of an incompetent patient are unknown and when no formal mechanism for making treatment decisions is in place, render such treatment as you believe to be in accordance with the patient's values or, if these are unknown, the patient's best interests.¹²²

The first statement seems to direct physicians to either follow an "advance directive" without turning to the incapable patient's SDM as required in Ontario, or alternatively, turn to the SDM (Proxy designation) who would then express the patient's "intentions". In the second

¹²⁰ Canadian Medical Association. "2015 Advance Care Planning Policy", para 2, online: CMA Policy <https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma_policy_advance_care_planning_pd15-08-e.pdf>.

¹²¹ *Ibid.*, para 28.

¹²² *Ibid.*, para 29.

paragraph, it appears to permit physicians to proceed of their own accord where wishes are not known, which, in Ontario, cannot occur except in an emergency (because there will always be an SDM available, whether someone named by the patient, a family member or the OPGT as an SDM of last resort).

In respect to the second statement, it should also be noted that provincial law in many other provinces also provides clear direction about who makes decisions for an incapable patient. This reduces the likelihood of physicians being placed into the decision-making role except in very limited circumstances.

Physicians look to the CMA for guidance and information about practice standards. In discussion with CMA for the purpose of this research paper, the points raised here were acknowledged. They emphasized that the materials refer physicians and patients to relevant provincial laws on advance care planning. However, a list of relevant provincial statutes or links to provincial materials are not provided in the CMA documents or on the CMA website. CMA has confirmed an intention to update the policy as part of a policy quality assurance process; at the time of writing, the policy remains on their website without qualification.

4. *The Office of the Auditor General of Ontario*

The Office of the Auditor General of Ontario (OAGO) describes itself as “an independent office of the Legislative Assembly that conducts value-for-money and financial audits of the provincial government, its ministries and agencies”.¹²³ The findings from the audits are shared in Annual and Special reports that provide information to Members of Provincial Parliament “to help the Legislature hold the government accountable”. In 2014, the OAGO Annual Report included a value-for-money audit that focused on Palliative Care¹²⁴. ACP is referenced several times throughout, being discussed as an area for improvement, and included as part of a recommendation. The report provides an appropriate definition for ACP, stating:

Advance care planning lets individuals communicate their values and wishes regarding health care in the event they become incapable of making such decisions. This planning involves discussions with family, friends and health-care providers, as well as appointing a substitute decision-maker who can speak for the person if the patient is unable to do so. For patients with a terminal illness, advance care planning helps ensure that they receive health care consistent with their preferences.¹²⁵

¹²³ See online: <http://www.auditor.on.ca/index.html>.

¹²⁴ Office of the Auditor General of Ontario, “Chapter 3, Section 3.08: Palliative Care. 2014 Annual Report of the Office of the Auditor General of Ontario,” Queen’s Printer for Ontario, 2014.

¹²⁵ *Ibid*, p. 276.

However, there are several examples where problematic language is used. To begin, the chapter on value-for-money references a 2014 report from the CMA, and specifically calls out “advance directives”, without noting that this term is not defined under Ontario law. Arguably, the use of the term “advance care plan” leads to inconsistent framing, and overemphasis of documentation, as illustrated in the following excerpt:

While only two of the hospices and one of the CCACs visited had a formal policy on discussing advance care planning with their patients, the other organizations visited all indicated that they would discuss advance care planning with their patients. However, we noted that once a patient creates an advance care plan, it is not readily available to all of the patient’s health-care providers. For example, the CCACs we visited kept a copy of patients’ advance care plans in their electronic information systems, which outside health-care providers, such as hospital staff and physicians, could not access¹²⁶.

While this paragraph appropriately promotes policies centered around discussions, the concern raised about access to an “advance care plan” suggests information needs to be provided in a written format. While wishes may be expressed in writing, the chapter does not clarify that there is no requirement for ACP wishes to be documented, or that these wishes can be communicated orally, or by any other means.

Later, the report appropriately describes how “having this information available to all of the patient’s health-care providers would better ensure that providers can readily obtain consent from the patient or their SDM to provide care in accordance with the patient’s wishes”.¹²⁷ This language properly suggests that ACP is being considered as distinct from consent to treatment.

In contrast, there is other messaging in the chapter which seems to conflate ACP and consent, as shown in the following example:

Although advance care plans are shared, other health-care providers have to go through lengthy records to find them. On this hospital’s standard discharge summary, which is automatically shared with the patient’s other service providers such as the family physician, one section indicates whether a patient opted to not receive cardiopulmonary resuscitation; however, a patient’s full advance care plan is not included.¹²⁸

¹²⁶ *Ibid*, p.277.

¹²⁷ *Ibid*, p. 277.

¹²⁸ *Ibid*, p. 277.

The reference to CPR implies the inclusion of treatment decisions in ACP, whereas in law, these decisions would be considered part of consent, and not ACP. It is also unclear what is meant by “full advance care plan”.

The OAGO reports typically receive media attention, which could then perpetuate misperceptions by the public. Given the overemphasis on documentation, this may lead people to conclude that informed consent is not required if there are written ACP wishes, or further embed misconceptions that a written ACP record either holds legal power, or can be used to direct health care practitioners; it cannot. More importantly, these reports provide recommendations to MOHLTC and other health care organizations, and as such, have implications for how care is provided.

E. Failure to Communicate the Patient's Present Condition

It is assumed that the intent of the health practitioner is to provide the best care, and uphold patient’s rights. However, there is evidence that health practitioners may not provide sufficient information about a patient’s present condition or treatment options to enable the patient (or the incapable patient’s SDM) to provide an informed consent. As outlined previously, this information is a prerequisite for informed consent. If a patient does not fully understand their condition, or how a treatment option may affect them, they may end up consenting to a more invasive treatment that they may not actually not want. While ACP may be viewed as a way to address patients receiving unwanted treatments, the real problem may be with the failure to properly explain the information required to get an informed consent.

There is no legal requirement for a patient to understand their condition as part of the ACP process. However, having a better understanding of the current context enables the patient to express wishes that will guide the SDM most effectively in making future health care decisions that are reflective of the patient. It also permits the patient to express wishes that would be more meaningful to health practitioners if they needed to apply them to respond in an emergency. Medical research confirms that patients may not understand their own health condition well enough to either provide an informed consent or to speculate about preferences for future care. In a communication with Dr. Jeff Myers, he advised that:

Many reports suggest a high prevalence of inaccurate understanding of illness among patients with serious illness. What a person understands about their illness and what he or she expects to occur substantially impacts both the care decisions

made and the overall outcomes. The multi-dimensional construct includes not appreciating either the incurable or progressive nature of the disease.¹²⁹

Dr. Myers went on to conclude:

The potential consequences of an inaccurate illness understanding however is a patient giving consent to specific treatments that otherwise might have been declined. For care decisions to be truly informed, patients would ideally gain an accurate understanding of their illness. This understanding shapes the context for which they can contemplate the key elements of a GOC discussion which includes their values, beliefs, and what they consider important.¹³⁰

F. Misunderstanding The Requirement For Capacity To Make Treatment Decisions

A prerequisite to both informed consent and discussion of ACP wishes is that these processes must be engaged in with a capable person. Practice tools do not always alert health practitioners about this capacity requirement, nor that it is their responsibility to make this determination. While they may legally delegate the assessment to another team member, ultimately they are responsible for it and must be satisfied that the consent was properly obtained.

Many misunderstandings about capacity remain. Some health practitioners do not understand that it is their role to determine capacity nor that it is a legal requirement of the HCCA. Others have expressed that they are not comfortable with completing capacity assessments. Some health practitioners erroneously believe they need a “capacity assessor” (as defined in the SDA), or a psychiatrist to complete the assessment.

An April 2016 decision¹³¹ of the Consent and Capacity Board is a good example of this lack of knowledge about capacity. Based on the experience of the authors, this is not an isolated case. Mrs. SW was a resident of a LTC home. Her legal counsel submitted that there was no finding of incapacity to consent to treatment. In the review of the finding of incapacity, the physician testified that the resident’s medical chart did not include any such finding of incapacity. She told the Board that since she had commenced treating the resident about two months before

¹²⁹ Weeks, J. et al. “Relationship between cancer patients’ predictions of prognosis and their treatment preferences” (1998) 279(21) *JAMA*, 1709; Zhang, B. et al. “Health care costs in the last week of life: Associations with end-of-life conversations” (2009) 169 *Arch Intern Med* 2009, 480.

¹³⁰ Myers, Jeff. “Speaking Notes on Advance Care Planning and Goals of Care” (unpublished).

¹³¹ In the Matter of SW, a Resident of Glenburnie Ontario, CCB Case 15-5454, Transcript of Evidence of Doctor KK., unpublished

the hearing, she had not done a “formal assessment” of her capacity to consent to treatment. She indicated that she had concerns about the resident’s capacity to consent and she believed the resident would likely be treatment incapable. However, she had never discussed the issue of capacity with the resident and never told her that she was incapable for this purpose. She also stated that since she was getting treatment instructions from the resident’s attorney for personal care, she assumed that the resident was incapable. The doctor stated “That’s the way it happens in a Nursing Home”.¹³²

G. Use of Team Members to Obtain Informed consent

Health care is often delivered in a “team” model. As a result, and as noted above, patients may be asked for consents to treatment by health care staff other than the health practitioner “offering” the treatment (i.e. the health practitioner who is ultimately responsible for obtaining informed consent). This may be appropriate, as long as the person obtaining the consent is able to provide the patient with all the information necessary under the HCCA to give an informed consent.

However, team members do not always provide sufficient information to get an effective informed consent. It has been noted that practices have developed in some LTC homes where the physician writes orders after they see residents, but rely on the registered nurse or other nursing staff, or unregulated staff (RNAs or PSWs) to make contact with the resident’s SDM to get the consent. Delegating informed consent is appropriate as long as the person delegated actually gets a legal, informed consent. The nursing staff may contact the SDM to relay the fact that the physician has made an order, but they may not explain the reasons for the order, the patient’s condition, or the rest of the information to get an informed consent. When this practice has been challenged at the Complaints committee of the College of Physicians and Surgeons, the College Committee panel has given mixed messages about its appropriateness.

In the Decisions and Reasons issued January 16, 2002, regarding a complaint by Kathleen Pogacar in respect of Dr. Christopher Pinto, the Committee stated that:

... it is a long-standing practice in nursing homes for physicians to give orders for patients’ medications, and for families, if they have concerns, to discuss these with attending physicians (albeit after the fact of the medication having been prescribed). The Committee does not find this situation to be unreasonable, given that a patient’s care may be compromised or undermined if there is a delay in providing timely treatment of a patient’s health crises until family members can be contacted for consent. Moreover, it is also standard practice in nursing homes for

¹³² *Ibid*, p.4.

nursing staff to alert patients' families to changes in a patient's medical condition. This practice stems from efficient management of a physician's workload. Moreover, it takes into account that practical reality that if the physicians were expected to personally contact patients' families, on top of his or her other duties, then instead of having very few physicians working in nursing homes (as in now the case), that small number would dwindle to virtually none simply because the work involved would be unreasonably burdensome.

Having said that, Ms. Pogacar is (strictly speaking) correct in asserting that, as Mr. Dineley's power of attorney for personal care, she ought to have been informed of both changes to medications, and the reasons for and possible side effects of any new prescriptions.¹³³

In this matter, there was no emergency that would warrant treatment without consent. The complainant Kathleen Pogacar asked the Health Professions Appeal and Review Board (HPARB) to review the CPSO Complaints Committee decision. In its reasons of August 2, 2002, HPARB referred the decisions back to the Complaints Committee for a reconsideration and new decision with supporting reasons. The Board stated:

While acknowledging that Dr. Pinto should have informed Ms. Pogacar about changes in medication, the Committee has overlooked the issue of consent. Consent goes beyond advising the holder of a power of attorney of medication changes. Consent requires some acknowledgement of an understanding of the purposes for the changes, and an agreement to these changes. The Committee has failed to address this critical aspect of the complaint. This is unreasonable.¹³⁴

On that reconsideration, the Committee concluded that the physician is responsible for getting consent to treatment from the appropriate person (in this case the SDM). However, in this particular case, consent was not required because this medication change was only a variation in medications for which consent had already been obtained. An independent peer reviewer who provided a report to the Committee stated that the practice of nursing staff informing SDMs of changes in medications is reasonable "provided that the attending physician is assured that the nursing staff person notifying the holder of the POA is knowledgeable about the problem and aware of the management option." A second review by HPARB agreed with the Committee's decision.

The second decision of the Committee did not directly address its statements made in the first decision that seemed to approve of this practice. While it was not strictly adherent to the requirement for informed consent, physicians and LTC home staff are left with a mixed message about the importance of informed consent and the responsibility of the physician

¹³³ In the matter of Mrs. SW, a Resident of Glenburnie Ontario CCCM 15-5454-01 April 29, 2016.

¹³⁴ *Ibid.*

when delegating the requirement to get an informed consent.

H. Reliance on Consents or ACP Wishes Obtained Elsewhere

This raises the issue of reliance on consents when the care of the patient is transferred to another health care organization or health practitioner. The health practitioner providing treatment to a patient is responsible for ensuring that an informed consent is obtained for the treatments delivered. This would include responsibility for treatments previously consented to, but continued while under the “watch” of a new health practitioner. This may involve a simple confirmation with the patient or SDM as to what drugs they have been prescribed and are taking. This is necessary for the new health practitioner to know when considering whether to propose changes to care in light of the patient's present health condition. The new health practitioner may reasonably presume that the previous health practitioner had obtained an informed consent to the continuing treatment, unless he or she discovers otherwise.

Reliance on previous consents may become problematic when the records on transfer indicate that the patient has “consented” to not having a treatment. Examples of this could include decisions about resuscitation, feeding tubes or other treatments at end-of-life. In some cases, the documentation to support these decisions may be limited. For example, it may be unclear whether a DNR order noted on a patient chart resulted from a full discussion that included a consent.

If there is an informed consent, it is not always possible to know if it was obtained from the appropriate person. The forms do not necessarily alert the health practitioner to consider the capacity of the patient in respect to the treatment. Further, some forms may list the SDM as “next of kin” or POA, which makes it difficult for the receiving health practitioner to identify the appropriate SDM. If the transferring health care organization or service were to include the hierarchy list of SDMs clearly on their forms, this would help provide evidence that the initial health practitioner was prompted to consider the correct SDM.

A clear example of this issue is the misuse of the Do Not Resuscitate Confirmation (DNRC) forms. The DNRC form was created to address a practical problem in the law. Emergency responders such as paramedics and firefighters are not regulated health practitioners. As such, they are required by law to attempt resuscitation if they find a person that has had a cardiac arrest. This must be done even if the patient or the patient's SDM has advised the emergency responders that the patient does not want this treatment. It is not within the scope of practice of the emergency responders to make determinations of whether or not resuscitation should be provided to a patient. However, emergency responders may now take direction from certain

regulated health professionals (physicians, registered nurses, registered nurses in the extended class, and registered practical nurses) to not resuscitate a patient.

To facilitate this communication from the regulated health practitioner, the DNRC form was created by the MOHLTC.¹³⁵ If signed by one of the appropriate regulated health practitioners, the DNRC form provides direction and authorization for the emergency responder to not initiate basic or advanced CPR and to only provide comfort measures.

By ticking one of these two boxes and signing the form, the health practitioners confirm that one of the following conditions has been met and is documented in the patient's health record:

- A current plan of treatment exists that reflects the patient's expressed wishes when capable, or consent of the SDM when the patient is incapable that CPR not be included in the patient's plan of treatment; or
- The physician's current opinion is that CPR will almost certainly not benefit the patient and is not part of the plan of treatment and the physician has discussed this with the capable patient or the SDM when the patient is incapable.

To help prevent fraudulent use of these forms, the forms are supplied by the Ontario government and have unique serial numbers. Although the forms facilitate communication to emergency responders that would permit them to comply with a plan of treatment that should have been consented to by the patient or the incapable patient's SDM, the question is whether the health practitioners signing the form has obtained an informed consent to that plan of treatment.

These forms are commonly used in LTC homes when residents may need transfer back and forth to hospital. However, a question worth posing is: Did the LTC home staff obtain the resident's CPR status after the appropriate health practitioner took all the steps to obtain an informed consent to no CPR? Based on the review of forms for this project and from the authors' experience, that is unclear.

It also leads to additional questions, for example: When the health practitioner ticks off the first box on the DNRC form, did that health practitioner personally have the consent conversation with the patient or did the health practitioner rely on a level of care form or other forms that are in the medical record completed by the resident or SDM with other non-regulated staff?

¹³⁵ See online: [http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/GetFileAttach/014-4519-45~1/\\$File/4519-45.pdf](http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/GetFileAttach/014-4519-45~1/$File/4519-45.pdf).

The concern is that CPR status may end up in a plan of treatment but proper consent was never obtained to No CPR. It was beyond the scope of this paper to research how this form is actually completed in practice to determine whether it is being completed as intended.

It has been observed that there are misunderstandings in the health system about the DNRC form. Health practitioners have described it as the “official” DNR form and the only one that is “legal”. However, it was created specifically for facilitating communications for emergency responders. Within a health care organization, it is not an appropriate way to record DNR status.

It has been observed that this form is being misused by some hospitals as confirmation of DNR status on admission. The plan of treatment that contained this DNR status that a patient had while living in a LTC home would no longer be valid, since a change in their health condition would have precipitated the transfer to hospital. As such, a new plan of treatment would be necessary for the treatment required at the hospital. It is possible that the patient may change their mind about the previous code status because of the change in their health condition that precipitated the transfer to hospital.

For a DNR form to be more useful across health care organizations, the form would need to include more information of the details about the patient's condition at the time the consent to DNR was given, and information about the process followed to obtain the consent. This would permit a new health practitioner to determine whether he or she could rely on it and whether a new consent discussion about CPR/DNR was necessary.

I. Team Members and Non-clinical Staff Engaging in ACP Conversations

Many ACP models encourage non-clinical staff and health practitioners other than the one responsible for treatment to have ACP conversations with patients. For example, the Gundersen Respecting Choices program (discussed further below), relies on volunteers, social workers, clergy, and students or special ACP ‘facilitators’ to initiate ACP conversations with patients. These conversations do not necessarily include any discussion with the patient about their present state of health, as those initiating the discussion may not be privy to that information. Those initiating the discussion are asked to obtain the patient’s ACP “wishes” for care written down in a form on admission to a health care organization or on contact with a health service.

One risk of this approach to ACP is that the concept of making wishes is presented in isolation, without connecting it to the spectrum of ACP, GOC and informed consent. As a result, it may

not be clear to the patient who is providing wishes that someday, an SDM will interpret those wishes as a condition of consenting (or not) to a proposed treatment on the patient's behalf. The question then is how useful that process is if the staff members engaging in the wishes conversation do not understand or neglects to explain to the patient the connections between ACP, GOC and informed consent.

One tool that appears to include non-registered staff as engaging in this process in LTC settings is the Prevention of Error-Based Transfers (PoET) tool. This tool came to the attention of the authors through a literature search and involvement of one of the authors in a LHIN-supported ACP project. The PoET project is described as "an ethics quality improvement project that prevents error based transfers between long-term care homes in the Central West Local Health Integration Network and the William Osler Health System".¹³⁶ The tool was developed to try and prevent LTC residents from receiving unwanted treatments they may not benefit from, and partially as a result of the use of Level of Care forms and because of errors related to consent, capacity, and substitute decision-making.

There are many excellent messages in the PoET project, in particular, reminders to staff in LTC that they need to get consent from residents or SDMs when treatment is proposed. Information on the detailed education that accompanies the implementation of the tools was not reviewed for this project; however, discussions with Dr. Oliver by one of the authors clarified that the requirement for informed consent before treatment is emphasized to LTC home staff which is precisely the right approach.¹³⁷

The PoET tool reviewed for this paper was the Preliminary Individualized Summary form. It includes a section to record Code Status, what to do before transfer to hospital, and Residents Wishes, Values, and Beliefs. Dr. Oliver indicated that she assists LTC homes in demonstrating to staff (who may not be physicians or other regulated health practitioners) how to complete this with residents. As such, it may not be a physician eventually proposing a plan of care to the resident, and this occurs before any discussion with the residents about their present health condition and possible treatment options (i.e. language of the HCCA). It was confirmed that this form may be completed by the incapable resident's SDM. While the form does not indicate that this is intended to be used to record what to do in an emergency, the authors confirmed that its purpose was for staff to have some guidance for an emergency response.

¹³⁶ The authors of this tool are ethicists Dr. Jill Oliver and Dr. Paula Chidwick.

¹³⁷ References to conversations in this section are in respect to a conversation between only Dr, Oliver and Judith Wahl In late July 2016.

The form appropriately reinforces the need to obtain consent from the correct decision-maker (resident if capable, otherwise SDM). The form also aims to assist in avoiding unnecessary and undesired transfer of residents to hospital, but does not provide the appropriate legal path for health practitioners and LTC to follow to achieve this goal.

Non-health practitioners may complete this form with residents on admission asking them for a decision about code status, which requires an informed consent to a plan of treatment. The health practitioner, who would speak to the resident's present condition, whether resuscitation is a treatment that might be proposed, and the risks, benefits, alternatives, is not involved. Given that the elements of informed consent are absent, code status cannot be legally obtained.

In contrast, the DNRC form that authorizes Emergency Responders to not provide resuscitation to patients when they are being transferred between health facilities must be completed by a physician or Nurse Practitioner only after they have had the informed consent discussions about resuscitation with the patients.

The form states that if the resident's health status changes, the Nurse Practitioner or Physician should be contacted to see if transfer to the hospital is indicated. It goes on to state that if transfer is proposed the resident should be asked for consent. If the resident is not capable at that time, then the resident's SDM should be asked for consent. In our view, it should also prompt a discussion about whether that treatment could take place at the LTC home rather than in a hospital. In law, the consent relates to the treatment proposed, not the transfer to hospital as stated in this form. To the extent that this form could be used to replace problematic Level of Care forms in LTC, it could be, if amended, an opportunity to refocus on the treatment, rather than the transfer issue, including the best place for the proposed treatment. No transfer will be necessary in a situation where the capable resident, or SDM, is consenting to a plan of treatment.

Resident's Wishes, Beliefs, and Values

Are the resident's wishes written down? No Yes

If 'Yes': 'Living Will' In Power of Attorney document Other: _____

This resident has expressed the following wishes related to current or future medical treatment:

Reported by: Resident SDM

This resident has the following values and beliefs:

Reported by: Resident SDM

The form provides a section for recording of the Resident's "Wishes, Beliefs, Values". Specifically, it states "This resident has expressed the following wishes related to current or future medical treatment", and then provides a check box to indicate whether these wishes were reported by the "Resident", or the "SDM". It is important to understand that in the HCCA, only wishes expressed while the individual is capable are required to be followed by an SDM making decisions for the now incapable individual. However, the form does not indicate whether the resident was capable when the wishes were expressed. It is unclear whether a regulated health professional that would be offering treatments to the resident is determining capacity before this section is completed. This also raises a concern if non-health practitioners are charged with recording the individual's wishes.

Who records wishes and whether these are capable wishes can have implications in the context of a health practitioner doing a Form G application to the Consent and Capacity Board. That application is done under section 37 of the HCCA to determine whether an SDM is complying with the requirements for substitute decision-making in the HCCA. The SDM is required to interpret prior capable wishes of the resident or act in the best interests of the resident if no possible or applicable wishes had been expressed by the resident when capable. Since the form does not indicate whether the patient was capable at the time the wishes were expressed, it would be difficult to determine whether the SDM was in compliance.

Additionally, the evidence of wishes on this form does not mean that the wishes are understood by the SDM in same way that the staff person wrote them down. The SDM is

required by law to determine if a wish is applicable to a particular decision to be made for the resident and this may require an interpretation of that wish, not a literal meaning of the wish. Further, including the SDM as an option to report the resident's wishes may be misleading for the person completing the form. SDMs cannot express wishes for a resident. Only the resident when capable may express wishes for him or herself. SDMs may only give or refuse consents to treatment and must make decisions for incapable residents, applying any wishes applicable to the particular treatment offered. Treatments must be offered first and then the SDM should be asked if the resident when capable had any wishes applicable to the decision to be made.

It is laudable that education is provided when the forms are introduced into health care organizations and that the forms include information on the requirement to obtain an informed consent before a treatment. However, the fact that wishes, values and beliefs are not consents should be made clear. In our experience, the emphasis on written wishes leads health practitioners and others to think that written wishes are more significant than wishes expressed in other ways. We have been advised that the form has been recently revised to remove reference to "living wills".

J. Tools Used Incorrectly as Consent or To Limit Treatment Options

The conflation of HCC, ACP and GOC was a consistent theme identified in both the tools assessment, as well as in our interviews and focus groups. Of concern, numerous tools contain incorrect language, or fail to clarify the distinction between these concepts. This may lead to the inappropriate use of these tools as consent, or to limit treatment options.

One of the challenges that exists in some LTC homes in Ontario is a requirement or request for new residents or their SDMs to complete "Level of Care" (LOC) forms. These forms are a generalized statement about the care the resident would want to receive in emergency situations. As previously noted, these forms are not consents as they are not specific to any treatments and not contextualized to the individual patient and their particular health condition. Level of care forms are usually not discussed in detail with patients before the signature and are too often completed by the patient or the patient's SDM (whether or not the patient is incapable of treatment decision-making) without a prior explanation of the patient's present health condition or the way the completed form will be used by the health team members.¹³⁸

¹³⁸ LCO Report 2014, *supra* note 82.

Use of LOC forms leave it up to the health practitioners to decide what specific care and treatments that the patient should receive based on a generalized direction. There is a serious question about whether the execution of these forms is a valid expression of a resident's "wishes" as that would depend on whether the resident was given information on how the LOC form would be used and under what circumstances. From the experience of the authors, these forms are often tick boxes, prepared with little or no discussion and then used differently depending on the interpretation of the LTC home staff and health practitioners.

Another significant problem that has been repeatedly identified is where wishes on a form appear to be driving the care provided. Some forms may correctly state that wishes are not consent to treatment. However, it is unknown if that statement is enough to ensure that wishes are not automatically used as consents or used to limit treatment options.

The following is an example of an LOC form from a LTC home that also appears to be used as a consent. Although it is referred to as an "advance directive", this form is completed after a "consent discussion" and refers to the elements of consent at the bottom. If this is used to record a consent it is unclear what the resident or SDM is consenting to, as the statements in the middle of the form are very general and only refer to a general approach to care and not to any specific treatments. If this is intended to record the results of an advance care planning discussion, the form is completed with either the resident or the incapable resident's SDM although advance care planning by law may only be done by a capable resident.

Advance Directive for Treatment

Resident's Name: _____
If the Resident is incapable, Substitute Decision-Maker (SDM): _____
Health Practitioner recording consent: _____
Date of consent discussion: _____

Name and Description of Directive

After discussion, the Resident or SDM has decided that in the event of life threatening illness, the Resident is to receive treatment as follows:

- COMFORT MEASURES ONLY**
- COMFORT MEASURES WITH ADDITIONAL TREATMENT AVAILABLE AT THE HOME**
- TRANSFER TO ACUTE CARE HOSPITAL WITHOUT CARDIOPULMONARY RESUSCITATION**
- TRANSFER TO ACUTE CARE HOSPITAL WITH CARDIOPULMONARY RESUSCITATION**

Informed Consent

I have been provided the following information by the Home:
Nature of the directive Yes Expected benefits of the directive Yes
Material risks of the directive Yes Material side effects of the directive Yes
Alternative courses of action Yes Likely consequences of not having the directive Yes

The example below is from a Health Links form used by health providers with patients that have multiple, complex conditions who are high users of the health system and likely use services across the health sectors (hospitals, community, long-term care).

My plan for future situations					
Future situations	What I will do	What I will <i>not</i> do	Who will help me	Telephone #	Review date
					YYYY-MM-DD
I have received information about advance care planning: Choose an item.					
I have a completed advance care plan: Choose an item. My ACP is located here:					
As I understand it, my advance care plan says:					
I have a Power of Attorney (POA) for personal care: Choose an item. My POA document is located here:					
Name of POA attorney:		Relationship to me:	Choose an item.	Telephone #:	

Health practitioners design an “individualized coordinated care plan” for each patient and work together with patients and their families to receive the care they need. This part of the form records the patient’s “plan for future situations”. This is not just about future health care but also includes what the patient may do if any particular events occur. This is a form of safety planning to help the patient anticipate possible urgent events to which he or she may need to respond.

The form records whether the patient has prepared a POAPC but does not include the HCCA SDM hierarchy making it appear that a patient would have to prepare a POAPC to have an SDM. If there is a drop down box in the line “I have a POAPC” that lists the hierarchy, then the form confuses “SDM” with “POAPC” which demonstrates lack of understanding of what is an SDM.

The form refers to ACP however it is unclear whether the users or authors of this form understand what ACP is and how it relates to the consent process. ACP is presented here as an exercise in preparing a written document although ACP, except for choosing a person to act as an attorney in a POAPC, may be done orally or communicated by alternative means, It is unclear whether the health practitioners using this form would understand that the ACP wishes are directions to the SDMs, not them as there is no statement on the form that the ACP wishes are not consents and are for the SDM to refer to when giving or refusing consent.

Another form that is also available as a computer application, is intended for use by health practitioners to explain to SDMs the requirements for decision-making set out in the HCCA. The

tool instructs the health practitioners to talk with the SDMs about the patient's previously expressed wishes before talking to the SDM about the possible treatment options. This is backwards as the SDM needs to know the patient's condition and treatment options first and then think about and apply the patient's previously expressed wishes that would be relevant. This tool may result in the health practitioners using the patient's general wishes to limit treatment options offered to the SDM for the patient.

There is a need for further research that focuses on how tools are used in practice, but that is beyond the scope of this paper.

K. Accreditation

Accreditation Canada works with health care organizations “to help them improve quality, safety, and efficiency so they can offer... the best possible care and service.”¹³⁹ While accreditation is voluntary, a review of the Accredimap Tool on the Accreditation Canada website indicates that many LTC homes, hospitals, and various types of health services in Ontario go through this accreditation process.¹⁴⁰ It is important to examine the accreditation standards related to consent and ACP of Accreditation Canada as organizations seeking accreditation will be influenced by those standards as to how they implement HCC and ACP.

The standards reviewed for this research paper were for:

1. Hospice, Palliative, End-of-Life Services
2. Long-Term Care
3. Residential Homes for Seniors
4. Leadership

Overall, the standards do reflect the legal framework in the Ontario legislation and emphasized the requirements to get an informed consent from the person if capable and from the person's SDM as determined by provincial legislation. The standards on capacity determination also reflected legally appropriate practice in Ontario.

However, some standards included references to “advance directives”. The term “advance directives” is not defined in the standards and it is not clear how the reviewer would apply the

¹³⁹ Accreditation Canada. “Corporate Overview”, online: <<https://accreditation.ca/corporate-overview>>.

¹⁴⁰ Many long-term care homes and other health care organizations are also accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) Canada and not Accreditation Canada. For this research paper we did not look at the CARF Canada Standards.

standards that refer to “advance directives” or how the health facility or organization would seek to comply with the standards with these references.

The standards in all four sets have similar standards for “appropriateness” and “client centred care” that refer to advance directives. Examples of these standards include the following:

Residential Homes for Seniors Accreditation Standards¹⁴¹

7.10 When residents are incapable of giving informed consent, consent is obtained from a substitute decision maker.

Guidelines

A substitute decision maker is consulted when residents are unable to make their own decisions, and an advance directive is used, where available, to ensure decisions are in line with the resident's wishes. In these cases, the substitute decision maker is provided with information about the roles and responsibilities involved in being a substitute decision maker, and given the opportunity to discuss questions, concerns, and options.

8.10 Each resident's advance directives including those that address the use of potentially life-sustaining treatment are documented in the resident's file.

Guidelines

Residents may have advance directives to guide certain or all decisions. The resident and family are informed, verbally and in writing, of their right to establish advance directives and how to do so. Advance directives are shared with providers within and outside the organization, as appropriate. Examples of potentially life-sustaining treatments include oxygen, hydration, and artificial nutrition.

Hospice, Palliative, and End of Life Services Standards¹⁴²

7.11 All advance directives including those that address the use of potentially life-sustaining treatment are recorded in the client's file in partnership with the client and family.

Guidelines

Clients may have advance directives to guide certain or all decisions. The client and family are informed, verbally and in writing, of their right to establish advance directives and how to do so. Examples of potentially life sustaining treatments include oxygen, hydration, and artificial nutrition.

7.12 Advance directives are communicated to providers within and outside the organization, as appropriate, in partnership with the client and family.

¹⁴¹ Accreditation Canada “Residential Homes for Seniors Accreditation Standards” 2015.

¹⁴² Accreditation Canada “Hospice, Palliative, and End of Life Services Standards” 2015.

Guidelines

Informal caregivers are included when communicating the advance directives.

7.13 Advance directives are regularly discussed with the client and family, and any changes are documented, in partnership with the client and family.

8.11 Each resident's advance care plan/directives, including those that address the use of potentially life-sustaining treatment, is documented in the resident's file.

Guidelines

Residents may have an advance care plan/directives to guide certain or all decisions. Advance care plans/directives are shared with providers within and outside the organization, as appropriate. Examples of potentially life-sustaining treatments include oxygen, hydration, assisted ventilation, and parenteral nutrition.

These standards assume that there is a common understanding about what “advance directives” are and that these documents are standard across Canada. There is an assumption that there is a “right” to create an advance directive in any province. However, such a document does not exist in Ontario. The closest equivalent, “wishes”, do not need to be in a written format. Wishes may be communicated orally, or by any other means, and changes can also be made orally.

As noted above, SDMs cannot create wishes for a patient. SDMs can only provide informed consent on behalf of the incapable patient. However, standard 7.11 suggests that SDMs may create “advance directives”. The standards also suggest that end-of-life treatment decisions are expressed through advance directives. In Ontario, decisions about such treatments are for the most part provided through informed consents. These decisions are in the context of the patient’s present condition and are not ACP wishes. This distinction between what is consent and what is an ACP is important because SDMs may provide consent to end of life care treatments if the patient is incapable.

L. Enforcement of Compliance with Health Legislation

There is also the challenge of enforcement to ensure compliance with the HCCA and other legislation relevant to informed consent and ACP. The MOHLTC is a key entity for managing enforcement. However, HCC and ACP are among many competing priorities in a large and complex health system, and the MOHLTC may not have the resources or ability to effectively monitor and enforce compliance with health legislation.

The *Long-Term Care Homes Act* is a good example of this. It includes a requirement that certain documents be “regulated documents” that must comply “with all the requirements of the regulations”.¹⁴³ This compliance is to be “certified by a lawyer”.¹⁴⁴ Regulated documents include “any document containing a consent or directive with respect to “treatment” as defined in the *Health Care Consent Act, 1996*, including a document containing a consent or directive with respect to a “course of treatment” or a “plan of treatment” under that Act.¹⁴⁵ It is presumed that the word “directive”, which is not defined in the legislation, includes ACP documents.

This requirement for certification by a lawyer was intended to ensure compliance with the HCCA and other relevant law. However, that has not proven to be the case. Notwithstanding, many LTC homes still have documents that are clearly deficient and non-compliant with the HCCA.

It would appear that these documents are not reviewed for content, for proof of certification, or for compliance with the HCCA by MOHLTC inspectors as part of their annual or spot inspections. In review of the Inspection Protocols used by MOHLTC inspectors, there are no protocols that include a specific review of “any document containing a consent or directive with respect to “treatment””.¹⁴⁶

There is reference to regulated documents in the Resident Charges Inspection Protocol but these refer only to the other type of regulated documents that are agreements in respect to charges for accommodation or services in a LTC home referred to in O. Reg. 79/10, s. 227 (1).

A January 29, 2016 memorandum from Karen Simpson, Interim Director, Long-Term Care Inspections Branch to all licensees and home administrators, states that on inspections and reviews triggered by complaints, Ministry Inspectors had found multiple instances of noncompliance with how LTC homes manage residents trust accounts and resident charges. The Ministry completed inspections focused on these issues and the memo was the report of those findings.

The memo references a finding that more than one home claimed to be unaware of the requirement for certification of regulated documents. One home could not produce evidence that the documents had been certified. There is no reference in the memo as to whether the

¹⁴³ *Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8, s. 80(1)(b).

¹⁴⁴ *Long -Term Care Homes Act, 2007*, S.O. 2007, c. 8, s. 80(1)(a) & (b).

¹⁴⁵ O. Reg. 79/10, s. 227 (1) under *Long -Term Care Homes Act, 2007*, S.O. 2007, c. 8.

¹⁴⁶ O. Reg. 79/10, s. 227 (1) under *Long -Term Care Homes Act, 2007*, S.O. 2007, c. 8.

inspectors reviewed the content and determined that the financial documents were legally correct. It would appear that the inspectors are depending on the certification alone for that. If homes were unaware that the financial documents defined as regulated documents had to be certified, it is likely that the homes were also unaware that the consent and ACP forms needed to be certified since both types of documents are listed in the same sections in the legislation and regulations.

In the Dignity, Choice and Privacy Inspection Protocol, the inspectors specifically look for evidence of whether the licensee has “fully respected and promoted the residents right to give or refuse consent to any treatment, care or services for which consent is required by law”. They also look for whether the resident was informed “of the consequences of giving or refusing consent”. However, it is not clear if this is done with a chart review or by asking staff and/or residents and SDMs whether they were provided with the information for an informed consent. If they were asked, it is not clear whether staff or residents or SDMs would understand the requirements for a valid informed consent.

It is interesting to note that when the *Long-Term Care Homes Act* was introduced, OANHSS developed a helpful set of precedents for their members and made them available publicly on the internet. This includes template consents and agreements created to fulfil these requirements (including certification by a lawyer), with the written caveat that to the extent a home deviates from the template, it can no longer be considered to be certified.¹⁴⁷ Even with such a resource available, some homes continue to deviate from the template without seeking the required certification; use certified documents that are legally incorrect; or possibly, deviate from a version that was properly certified as being legally correct.

In the course of our ordinary work at ACE we have raised concerns to the MOHLTC about practice tools used in hospitals that in our opinion were not compliant with the HCCA. There is a need for targeted research to define the scope of authority of the MOHLTC, and more specifically, to identify whether it should include addressing concerns about HCC and ACP practices in the hospital setting. That was beyond the scope of this paper.

M. Limited Penalties for Non-Compliance and Good Faith Exemptions

In the HCCA, all health practitioners are protected from liability if treatment is administered, or not administered, or withheld or withdrawn on the basis of consent or a refusal that a health

¹⁴⁷Ontario Association of Non-Profit Homes and Services for Seniors (OANHSS). “Consent to Treatment Package”, Long-Term Care Home Implementation Member Support Project (December 2010)
[https://www.google.ca/?gws_rd=ssl#q=Consent+to+treatment+Member+Support+Project+\(December+2010\)](https://www.google.ca/?gws_rd=ssl#q=Consent+to+treatment+Member+Support+Project+(December+2010)).

practitioner “believes on reasonable grounds and in good faith to be sufficient”.¹⁴⁸ Similar good faith exemptions are also found in the HCCA, concerning emergency treatment.

Only two cases were found that would provide more insight into what these sections mean: the Supreme Court of Canada decision in *Cuthbertson v. Rasouli*,¹⁴⁹ and a decision of the Health Professions Appeal and Review Board *EGJW v MGC*¹⁵⁰ that cites the decision in *Rasouli*. Both cases involve consideration of whether the definition of treatment included the withdrawal or withholding of treatment; and specifically, whether physicians needed to get consent to place a DNR order on the patient's chart.

In *Rasouli*, the Chief Justice, writing for the majority, refers to this section in the discussion on whether the definition of treatment includes withdrawal of treatment. She states at para. 50:

The scheme of the HCCA suggests that the legislature contemplated that withdrawal of treatment requires consent in some cases. One form of treatment identified under the HCCA is a “plan of treatment”, which is a defined term under the statute: s. 2(1). A physician may obtain consent for a plan of treatment that provides for various treatments and may provide for the *withholding* or *withdrawal* of treatment: ss. 2(1) and 13. Section 29(3) then states that if a treatment is withheld or withdrawn in accordance with a plan of treatment that the physician believes reasonably and in good faith was consented to, the physician is not liable for withholding or withdrawing the treatment. This provision would serve no purpose if consent were not required for the withholding or withdrawal of treatment in some circumstances.¹⁵¹

This decision does not interpret what is meant by “good faith” but refers to this section of the HCCA as support for the decision that withdrawal of treatment requires informed consent. This could mean that if a physician places a DNR order on the chart without seeking consent that action would not be “in good faith”. There may be argument for a physician who believes, on reasonable grounds that they have acted in good faith to obtain a consent or refusal of treatment. However, it is necessary for the physician to still seek consent or refusal.

¹⁴⁸ HCCA s. 29(1)(2)(3).

¹⁴⁹ *Cuthbertson v. Rasouli* [2013] 3 SCR 341, 2013 SCC 53 (CanLII), available online at : <http://canlii.ca/t/g10hr>

¹⁵⁰ *EGJW v MGC*, 2014 CanLII 49888 (ON HPARB), available online at : <http://canlii.ca/t/g8s9m>.

¹⁵¹ *Ibid.*, para. 50.

The HPARB decision was the second review of a decision of the Inquiry, Complaints and Reports Committee of the College of Physicians and Surgeons of Ontario in the same matter. The complaint to the CPSO was made by the Applicant who was SDM for a patient (her father) who had directed the physicians to change a previous DNR order to a Full Code. This direction had been followed, however, shortly after transfer from ICU to the Medical Unit, physicians placed a DNR order on the patient's chart without consulting with the Applicant. One of the physicians had called the applicant and left a message but did not indicate that a DNR had been placed on the chart nor did he express any urgency. He indicated that nothing had changed and asked the applicant to contact him. When the applicant visited her father he was in respiratory distress. She requested help from a variety of sources but no medical interventions were made to save the patient, who died from a cardiac arrest.

The CPSO Committee considered the complaint on two occasions. The Board returned the Committee's first decision for further consideration because the Committee failed to consider the requirements of the *HCCA*, College policy, and the relevant policies at the particular hospital. The Committee considered these matters in its second decision and again decided to take no further action on the complaint. This decision of the HPARB was the review of the second decision of the CPSO committee and they again decided to return the second decision to the CPSO Committee for a reconsideration. In addition, the HPARB also recommended that the CPSO review and revise its policies to ensure compliance with the requirements of the *HCCA*.

The Board concluded on the review of the second CPSO Committee decision that the CPSO Committee had emphasized the physician's compliance with the hospital policy and, to a lesser extent, College policy and that they failed "to ascertain and accord priority to the requirements of the *HCCA*".¹⁵² The hospital policy stated "that a DNR order may be made without consent, subject to dispute resolution procedures if necessary. The Committee concluded that College policy was unclear on this point, but that it would be contrary to the policy against providing futile treatment if the Respondents were required to provide CPR until dispute resolution procedures were exhausted."¹⁵³

HPARB concluded that the CPSO Committee's analysis did not consider that the complaint was "that a DNR order was made by the Respondents despite "Full Code" instructions the Applicant had given as SDM. The Applicant's instructions were changed without prior discussion with, or the consent of, the Applicant, and as a result the Applicant could not object in a timely way".¹⁵⁴

¹⁵² *Ibid*, para. 39.

¹⁵³ *Ibid*, para. 39.

¹⁵⁴ *Ibid*, para. 40.

The HPARB decision emphasizes that the HCCA places an onus on physicians “to object if they consider that the decisions of the SDM are not in the best interests of the patient. College and hospital policies are supposed to give effect to the law. If hospital and/or College policies authorize the Respondents’ actions, then these policies are, to that extent, inconsistent with the law.”¹⁵⁵

The HPARB decision confirms that law “takes precedence over policy in the event of any inconsistency”¹⁵⁶ and that the CPSO Committee gave “scant consideration to the requirements of the HCCA and the consent to treatment requirements it establishes”.¹⁵⁷ Further, the HPARB stated:

The decision of the Supreme Court of Canada in *Rasouli* clarified the operation of the law but did not change it either retrospectively or prospectively. Although a good faith misunderstanding as to the nature of a legal duty may be relevant to Committee’s determination as to the nature of remedial action that may be required in these circumstances, it does not excuse a failure to comply with the law per se.¹⁵⁸

The Board held that,

The Respondents were required to obtain consent from the Applicant as SDM before replacing the “Full Code” order with the DNR order regardless of their view as to the futility of treatment, and in the absence of consent were required to invoke the dispute resolution procedure under the HCC.¹⁵⁹

The Board also cited the section from the *Rasouli* decision above in respect to the requirement for withdrawal and withholding of treatment.

Based on this HPARB decision, if the health practitioner fails to legally obtain informed consent, but follows prompts on a legally incorrect practice tool that is a health facilities standard tool, it could be argued that the health practitioner had a good faith misunderstanding of the legal duty. However, a good faith misunderstanding does not excuse a failure to comply with the law but has implications for any penalty or remedial action required.

Complaints to professional Colleges could be made by patients if a health practitioner failed to get an informed consent prior to treatment. The brief research done for this paper showed that

¹⁵⁵ *Ibid*, para. 41.

¹⁵⁶ *Ibid*, para. 42.

¹⁵⁷ *Ibid*, para. 41.

¹⁵⁸ *Ibid*, para. 53.

¹⁵⁹ *Ibid*, para. 51.

the common results of such complaints was that the health practitioners were counselled to better communicate with patients and SDMs. Whether this type of result has a deterrent effect is open to question. Additionally, the decision in *EGJW v. MGC* illustrates that at least one of the professional Colleges prioritized compliance with hospital policy and College policies over compliance with the HCCA.

It is interesting to note that the HCCA includes penalties but all of these are with respect to actions by the SDMs. An SDM can be guilty of an offence and on conviction liable to a fine of up to \$10,000 if he or she has represented that they are the person entitled to be the SDM and do not act in accordance with the HCCA. For example, if they knowingly misrepresent wishes someone has expressed with respect to treatment, admission to a care facility or a personal assistance service, or if they knowingly fail to follow the wishes of the patient expressed when capable and applicable to the circumstances when giving or refusing consent on behalf of the patient

Raising this issue is not intended to suggest that there should be penalties for health practitioners or that the protection against liability sections should be changed. Instead, this underscores the importance of ensuring legally accurate practices tools and educating health practitioners, patients and SDMs to strengthen compliance with informed consent practices.

N. Limited Legal Review

Although practice tools on HCC and ACP are at the intersection of law, health care and ethics, there appears to be limited consideration for legal issues, and legal involvement is rare. Many of the stakeholders we interviewed confirmed that materials had not undergone any legal review. Ethicists or health practitioners may have been asked to review the documents or are retained to manage projects that result in tools or educational materials. This has led to legal errors in the new materials as well as reliance on resources that are not legally correct in Ontario. Based on the anecdotal responses obtained, lawyers are not regularly retained to be part of the tool development process nor are they included as part of research teams involved in tool implementation and evaluation. Further, legal reviews of any type were not considered necessary. It is unclear if this is a failure to see the legal elements of HCC and ACP, or an overemphasis on the clinical processes.

ACE has had direct experience with the refusal of some health practitioners to include detailed information on the law about consent and health decision-making in educational materials. In one major national program on end-of-life care, the original educational materials had been designed to provide generic information that was applicable across Canada. It also included

provincial specific information to assist health practitioners to understand how to operationalize the information in their own jurisdiction in accordance with provincial law. That detailed provincial specific information was removed before publication. The reason given was that the details were “too confusing” and not necessary to implement the palliative care education information. The only reference in the text was a warning that there may be differences in provincial law therefore health practitioners should look at the legislation in the province in which they provide services for more information. This kind of approach, while accurate, is potentially incomplete and may contribute to misunderstandings about the operationalization of consent and ACP in practice.

Some groups active in issues related to consent and ACP have recognized this need to pay more attention to the differences in provincial and territorial law when producing tools and materials. Canadian Hospice and Palliative Care Association started by producing a generic Advance Care Planning workbook but welcomed requests from provincial hospice and palliative groups for those groups to tailor the generic materials to better reflect provincial differences. There are now Ontario and BC versions of that generic guide available on the CHPCA website.

The HCC and ACP Community of Practice of Hospice and Palliative Care Ontario actively promotes improvement in the implementation of HCC and ACP in the health system in Ontario. It encourages health practitioners and health organizations to review any existing tools, policies and educational materials that they use to determine if all those materials are compliant with the HCCA. The Community of Practice also offers to provide a written review of others materials at their request to assist them in their own reviews.

O. Reliance On Peer Reviewed Materials Without Adaptation

Health practitioners generally emphasize that they need to engage in “evidence based practice”. However, the published peer reviewed materials do not always reflect the elements of the Ontario law and the legal issues are not considered in the research. The fact is that HCC and ACP fall under provincial law and there are provincial variations that may not be understood by the researchers or may be ignored. Many research initiatives include researchers in multiple provinces.

There is collaborative research occurring in BC, Alberta, and Ontario that may not consider the detailed differences between the provinces laws or practices in the area of HCC and ACP. This is particularly significant when researchers from these three provinces work together because Alberta Health uses a GOC designation form that is also titled an ACP document but appears to

be used as a consent. This form appears to be used in BC as well.¹⁶⁰ In Ontario, this tool would not meet the standards for an informed consent and is not an appropriate ACP tool. At least one hospital in Ontario whose practice tools we reviewed is using the Alberta form with no revision.

One set of practice tools and an organized “system” for ACP that has had influence internationally is the “Respecting Choices” model. The model was developed by the Gundersen Health System, a not-for-profit corporation located in La Crosse, Wisconsin. It is described on their website as an “internationally recognized, evidence-based model of ACP that creates a health care culture of person-centered care; care that honors an individual’s goals and values for current and future health care.”¹⁶¹ Unlike the other tools we have described, Respecting Choices is a multi-component intervention, all of which must connect and function together for the model to be effective. There are four components that comprise the building blocks of this model:

1. *Organizational and Community engagement*

Community engagement focuses on raising public awareness through the use of consistent and repetitive messaging to emphasize the importance of ACP for all adults.

Organizational engagement refers to the active involvement of all religious, ethnic, and cultural communities, local advocacy groups, and organizations that provide care in public awareness efforts.¹⁶²

2. *Education*

Education is focused on providing communication skills training to facilitators, as well as other team members involved in ACP using a competency based approach. This also includes broader stakeholder education.

3. *System Infrastructure*

Systems changes are primarily focused on documenting ACP, to ensure that a person's preferences are recorded and available across care settings.

4. *Continuous Quality Improvement*

¹⁶⁰ See comments about GOC form in section on differences between ACP, GOA and HCC above.

¹⁶¹ Gundersen Health System. “Respecting Choices® Advance Care Planning”, online: ACP Resources <<http://www.gundersenhealth.org/respecting-choices>>.

¹⁶² Respecting Choices History/Overview, 2007, Gundersen Lutheran Medical Foundation Inc., <http://www.eutanasia.ws/hemeroteca/z9.pdf>.

Continuous quality improvement focuses on ongoing monitoring and evaluation to ensure appropriate implementation. This includes defining quality ACP outcomes, and providing guidance on the collection and use of data to create changes.¹⁶³

Fraser Health Authority in British Columbia and Calgary Health are listed on the website as having taken the training and implemented Respecting Choices in their health facilities. The Fraser Health Authority materials are often cited as a resource in many ACP education materials for the development of practice tools in Ontario.

The question is whether the Respecting Choices program, without amendment, would be appropriate for use in Ontario. In our view, it would not. Respecting Choices makes no distinction between ACP and informed consent. For example, end-of-life care discussions between health practitioners and patients are described as ACP although the discussions are about a plan of care to address the patient's current care needs. As a result, ACP in this model refers to patients making health decisions for themselves in advance and does not include a role for the substitute decision-maker.

This ignores the requirement for informed consent at the time of treatment. There is emphasis in Respecting Choices on written advance directives which would be followed by health practitioners once the patient was incapable. This permits health practitioners to interpret and determine when to apply the patient's general wishes rather than get an informed consent. Although Respecting Choices has been touted as patient focused, the HCCA model of informed consent and ACP if followed ensures that the patient's voice is more effective as it emphasizes contextualized decision making and does not give authority to health practitioners to make decision for patients except in emergencies when consent cannot be obtained.

VI. CONCLUSIONS AND RECOMMENDATIONS

Informed consent is fundamental to patient-centred care, but the various issues and challenges identified in this paper suggest that it is often neglected. Efforts that are meant to empower patients place little to no emphasis on HCC and embed a model of ACP that is not aligned with Ontario legislation. As a result, patient's rights to make informed decisions about their own care may be compromised.

In other jurisdictions, the model of ACP is not integrated along a continuum with GOC and HCC. This may result in patients being asked to make statements about future care without any context and without key information. This is especially problematic in jurisdictions where health

¹⁶³ *Ibid.*

practitioners rely on documents to direct care provided to incapable patients because out of context, uninformed statements may be used to make decisions for the patient.

From a legislative perspective, the HCCA strikes an important balance. In Ontario, the requirement for informed consent prior to treatment being offered not only ensures that patient autonomy is respected, but it also ensures that treatment decisions are contextualized. The fact that ACP and HCC are interconnected in Ontario is also beneficial, because this enables important preparation for the SDM to ensure that any decisions they make on behalf of the incapable patient are also contextualized as well as maintain that patient's preferences.

In our view, the HCCA is sound, and does not warrant any major changes. Based on what we identified in this paper, the HCCA has not been adequately embedded into the health system, and the issues are primarily linked to implementation, and enforcement.

Our conclusion is that a set of standardized practice tools would not be possible. To begin, tool development is so widespread, it has become an "industry". Researchers as part of their research studies, lawyers for both health practitioners and the health facility side and patient and LTC resident sides, various health professionals and others working in the health system such as ethicists, physicians, social workers, and nurses are all involved in the creation of practice tools. There are also national and international companies in the business of creating health records systems and education packages, both containing various types of practice tools, who heavily promote those products to health practitioners and health care organizations. These are advertised as readymade sets of tools that save time and money, increase work efficiency, and remove the burden of creating their own systems. This would in our opinion be impossible to stop.

Furthermore there is no one set of "perfect" practice tools. There are different types of health practices and services so everyone sees need for variants on a tool as no one set of products would meet all needs. It is possible to list a set of types of practice tools that are commonly requested by health practitioners, by patients, patients' families and future SDMs, and by other players in the health system as broadly defined. We have included such a list at the end of the recommendations but it is by no means a definitive list.

What would be beneficial is implementation of a systems approach to effectively change health care organization, health practitioner and public behaviours. We have noted the comprehensive and effective nature of the Gundersen Respecting Choices model in incorporating specific messaging and implementation of a common program for ACP.

As stated earlier in the paper we are not recommending the content from that model as it does not reflect Ontario law, nor does it consider, understand, or appreciate the Ontario HCC, ACP, GOC framework. Of concern, the influence of Respecting Choices on the Fraser Health Authority and Alberta ACP programmes, which are frequently touted as models to emulate, may actually be the source of a lot of the misunderstandings about informed consent and ACP in this province and amongst health practitioners and researchers in particular.

The challenge in a systems model is determining who would be responsible for it and who would fund it. With all the players in the health systems having so many accountabilities to so many different players as described in the paper, no one body would have the power and influence and funding to undertake such a comprehensive initiative across all of Ontario. However it is an approach that might be possible on a different scale with modifications within a more limited region (such as a LHIN), a city or even within a health organization.

Given our respective areas of expertise, we are not in a position to make broader system recommendations, and as such the focus of our recommendations is on specific areas where we believe the legal framework for health decision-making could be better integrated into the health system.

We acknowledge that in addition to the research conducted here, these recommendations are made as a result of our experience, which may create some limitations. Others may have recommendations from different perspectives of how to accomplish this goal.

A. Terminology

In order to focus health practitioners on implementing patient centred care, they must understand that this requires compliance with the HCCA. One important step in doing this is to use the terminology and language of the HCCA in all practice tools of any type used in Ontario. Terms such as “advance directives”, “living wills” and any nomenclature derived from other jurisdictions, that have no legal foundation in Ontario, should be eliminated from all practice tools. For this to be accomplished, this must be championed by health sector leadership including but not limited to the MOHLTC, HQO, LHINs and Health Links, all health care organizations, including hospitals and long-term care homes, all health care professionals organizations (OMA, CMA, RAO, CNA, etc.) and regulatory Colleges. HPCO’s HCC ACP CoP has developed some key resources that help to identify some of the problematic language, and can also be used to screen existing practice tools to ensure compliance with Ontario’s legislative framework.

B. Education

All stakeholders (including health practitioners, health care organization leadership responsible for professional practice, policy-makers, as well as patients, SDMs and the general public) must receive education on HCC, GOC and ACP (as described in Ontario law) and the interrelationships between these three concepts.

The education provider will vary according to audience. It is impossible to recommend any particular body or authority to have responsibility for this education however health sector leadership of all types should be encouraged to recognize this need and in particular that the education must reflect Ontario law. Funding for education or educational materials should not be provided by funders unless there is assurance that the education programme and materials are legally accurate.

It can be said that providers of such education must include universities and colleges that train health practitioners and allied health providers. Education on HCC, ACP, and GOC should be a mandatory part of the curriculum in college, undergraduate, post-graduate and continuing education.

Training for health practitioners must include communication skills so that they can confidently engage patients and SDMs in ACP conversations and GOC discussions, and effectively obtain informed consent. It must include details on what is informed consent as it is defined in the law, the health practitioners' responsibility to obtain it from the right party (patient if capable, appropriate SDM if patient incapable) and the risks of engaging unregulated staff in that process. Training must include information on mental capacity for treatment, how to assess capacity, who the SDMs are, and how to determine the appropriate SDM in law. Special attention must be paid to ensure that HCC, ACP and GOC are not conflated.

Public education could be provided by many different types of organizations and individuals (legal clinics, community organizations, patient rights groups, private organizations and so on). Who provides the education is not as important as promoting that the content must be Ontario- specific and reflect Ontario law. It is important that it be commonly understood that consent and ACP have a legal framework and are not just part of ethical or clinical practices and that this legal framework is provincial and will necessarily vary in detail across Canada.

Education for patients and SDMs should focus on the same fundamental aspects as outlined for health practitioners. Patients and SDMs also need information on their rights and roles in these

processes so that they can effectively engage with health practitioners in consent, GOC and ACP discussions.

C. Legal Accuracy of Practice Tools

Practice tools supporting HCC, GOC and ACP must be legally accurate, whether adapted from another jurisdiction for use in Ontario or not, and must have legal review. We do not recommend “certification” of all practice tools by a lawyer as required for “regulated documents” under the general regulation to the LTCHA. However, health leadership funding for HCC and ACP initiatives must require legal accuracy as a condition of funding. Any body regulating or providing oversight of health services providers must also require legal accuracy of any type of practice tool and include review or inspection of such practice tools as part of the oversight or regulatory process.

D. Enforcement

Recognizing that there is no single body responsible for HCCA compliance, the legal framework for HCC, GOC and ACP must be reinforced system-wide at all levels, including with MOHLTC, LHINs, HQO, health regulatory Colleges, professional and health sector associations, hospital boards and senior leadership, long-term care home operators, senior leadership in other health care organizations, patient ombudsman, patient advocacy groups, Accreditation Canada, other accreditation bodies and others. All of these stakeholders are responsible for promoting compliance to effect necessary changes.

We are not in a position to advise how this could or should be done as the various authorities or organizations listed above would each know the most effective way of doing this within their own sectors. However, saying this, we do submit that certain health sector leadership such as the MOHLTC, LHINs and HQO to name only three could play a major leadership role in promoting HCCA compliance as fundamental to all health initiatives.

We encourage health sector leadership to think creatively about what we are calling enforcement using existing tools in their sector. One example of an effective and creative initiative to effect change in HCC and ACP practices in a LHIN (Haldimand, Norfolk, Hamilton Brant), was a requirement that all RNs employed in any long-term care home take a LHIN developed and approved online training course on the fundamentals of HCC and ACP as defined in Ontario. The program included an online test of the learnings and to pass the test, the trainee had to score a minimum of 80%. This was a requirement in the Service Accountability Agreements for long term-care homes. This is just one example of how to leverage existing

requirements to have impact in this area. This was simple and easy for front line staff to undertake as the course could be taken in small segments whenever time allowed, and of significance to this research paper, was legally accurate. It did serve to stimulate interest in change in practices and an increased understanding of HCC and ACP.

In closing, we offer the following chart as guidance to suggest the content areas that should be considered for inclusion when developing practice tools. This is not to suggest that all areas would need to be included in one tool. Instead, consideration should be made to ensure that a combination of tools would cover all areas, or that implementation of the tools would be paired with appropriate education to ensure sufficient coverage of the content areas.

Table 3. Recommended Content Areas for ACP, GOC and HCC Practice Tools	
Target Audience	Recommended Content Areas for Practice Tool Development
Health Practitioners	<ul style="list-style-type: none"> ● Requirements for informed consent ● Interrelationship between Informed consent / GOC / ACP ● Health practitioner’s role in ACP ● How to have ACP conversations with patients and their future SDMs ● Privacy and ACP and HCC ● How to have GOC discussions ● How to obtain informed consent ● What is capacity for treatment and how to assess capacity ● Obligation of health practitioners to provide rights information to patients found incapable for treatment and how to do that ● SDMs - who are SDMs; how to determine who is the right SDM for a patient; what to do if there are multiple SDMs or conflicts between SDMs; When the OPGT is the SDM; How SDMs are required to make decisions ● Health practitioner legal obligation to explain to SDMs their responsibilities when decision making for incapable patients (Following applicable wishes- best interests)
Patients	<ul style="list-style-type: none"> ● What is Informed consent ● What are GOC and the interrelationship with informed consent ● What is ACP and its interrelationship with informed consent ● SDMs - What is an SDM; How to determine your automatic SDM; Choosing an alternative SDM by preparing a POAPC; How SDMs are required to make decisions; communicating with your future SDM ● How to change your SDM ● Specific treatment information e.g. Resuscitation, Tube Feeding, other End of Life care
SDMs	<ul style="list-style-type: none"> ● Who can or can't be an SDM and why; requirements to be an SDM; what happens if an SDM refuses to act or is not available or no longer meets requirements to be an SDM ● The role of the SDM in informed consent; information the SDM is entitled to receive (privacy and right of access to information when an SDM) ● Responsibilities of the SDM (Must an individual agree to act as SDM?)

	<p>Who meets the legal test to be an SDM, and what does it mean to be willing, available, etc.)</p> <ul style="list-style-type: none"> ● How to “retire” as an SDM
<p>Health care organizations</p>	<ul style="list-style-type: none"> ● Policies on Requirements to Obtain Informed consent and how that is to be recorded ● Forms to prompt obtaining Informed consent and record informed consents ● Policies on ACP and GOC and interrelationship between HCC, ACP, GOC ● Clarification that ACP may be done orally , communicated by alternative means , and not limited to written documentation ● Process to obtain engage in ACP, to discuss GOC , to obtain Informed consent ● Forms to record ACP conversations with clear warnings that ACP conversations are not Informed consents ● Forms to record No CPR/ DNR consents and other end of life treatment consents ● Forms that record patients future SDM(s) as per HCCA Hierarchy

SCHEDULE A: ACKNOWLEDGEMENTS

The production of this research paper proved to be a greater undertaking than expected, in part because of heightened interest in ACP as a result of the introduction and passage of amendments to the *Criminal Code* to permit Medical Assistance in Dying (MAID) during the same period scheduled for the work on this paper. There was much debate particularly in the Senate about the use of “advance directives” to permit pre-consent to MAID which in part resulted in a great deal of work for the authors of this paper in their own workplaces on issues related to health care consent (HCC), advance care planning (ACP), and goals of care (GOC); as such pre-consent would not reflect the Ontario legal requirements for informed consent.

This also put a spotlight on the degree to which the laws governing HCC, ACP, and GOC are misunderstood in the Ontario context. It focused attention on the practice tools produced or endorsed or used by a wide range of authorities, including but not limited to researchers, LHINS, professional organizations, and other tools that may contribute to these misunderstandings. Given that this was the focus of the paper, the work occurred in the context of a dynamic environment.

The authors must acknowledge a number of individuals and organizations, without whose help we would not have been able to complete this research paper.

First and foremost, the authors acknowledge and thank the Law Commission of Ontario (LCO) for selecting for funding this research proposal. We also thank the LCO for its patience in permitting us to complete the paper to a standard that would satisfy both the LCO and the authors.

We trust that we have produced a paper that will meet the LCO expectations and contribute to the LCO Project on Improving the Last Stages of Life.

The authors also thank the many people who have assisted with our research, participated in focus group meetings, reviewed parts of the paper, provided us with documents and policies, and have taken the time to discuss these important issues with us, including:

- Law students: Candice Camilleri and Nareh Ghalustians (Osgoode Hall Law School, York University) who conducted legal research for this Paper, assisted with and did interviews and focus groups, and played a primary role in the review of 100 practice tools sample collected for this project. We also thank law students Ruchi Punjabi (University of Windsor) and Aditya Dhingra (University of Alberta) that did legal

research and other tasks related to the production of this paper.

- Patient Advocates Focus Group Participants: Samantha Peck (Family Council Association), Elizabeth McNabb (OCSCO), Erin Harris (Older Women's Network), Peggy Hawthorn(USCO), Sharon Danley (DAWN) Neil Stuart and Andrew Ignatieff (Patients Canada), Donna Turner (Rainbow Health Ontario), Maureen Aslin (End of Life Planning Canada).
- Lawyers Focus Group Participants: Mark Handelman, Jane Meadus. Edgar-Andre Montigny and Marshall Swadron.
- Individuals who agreed to be interviewed including physicians, ethicists, and researchers.
- Health Organizations and individuals contributing Forms and Policies: We would like to thank all health organizations and individuals who provided us with practice tools for this project. It was agreed that all such contributors would remain anonymous. It should be noted that some practice tools were obtained by the authors independently from this formal request for practice tools from our own research on the internet or from other sources.
- ACE and DDO Staff, who assisted us and supported this initiative.
- Dr. Jeff Myers who shared research with us as well as an unpublished paper.

If we have missed anyone, we apologize. This error would be only an oversight on our part. We thank each and every person who contributed in any way to this research paper.

SCHEDULE B: THE AUTHORS

Advocacy Centre for the Elderly (ACE) - Judith Wahl

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, and in particular, Judith Wahl, have been directly involved in many of the major initiatives in Ontario on these issues including the Attorney General's Advisory Committee on Substitute Decision-Making for Mentally Incapable Persons (commonly known as the Fram Committee), the Ontario Strategy for Alzheimer Disease and Related Dementias, Initiatives #2 and #7 on Physician Training, and Advance Directives on Care Choices, the Ontario Medical Association President's Advisory Panel on End-of-Life Care, and the Advisory Committee for the Law Commission of Ontario Project on Legal Capacity, Decision Making and Guardianship.

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. Along with Tara Walton, Judith is an active participant and member of the HPCO HCC and ACP Community of Practice and Leadership Table.

Dykeman & O'Brien LLP (DDO Health Law)

DDO Health Law is a boutique health law firm located in Toronto, serving primarily institutional clients including 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 (including medical assistance in dying), and difficult situations involving patients/residents/clients and their 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 home). Mary Jane teaches, with Michele Warner of the Centre for Addiction and Mental Health, the Mental Health Law course in Osgoode Professional Development's Health Law LL.M. program. She sits on the Board of the Alzheimer Society of Toronto and the Research Ethics Board of Canadian Blood Services. She is past Board Chair of the Anne Johnston Health Station, a community health centre serving seniors, the barrier-free (clients with mobility issues) and youth. Mary Jane and her law partner Kathy O'Brien strive to simplify the health system, bringing training and information to health care organizations, health practitioners and to the general public, both patients and caregivers.

Tara Walton, Family/Caregiver Representative

Tara Walton provides a unique perspective, sharing insights and information from her experience as a family caregiver, as well as a diverse background in oncology research, palliative care, and health policy. In the fall of 2014, Tara spent 3 weeks in an Intensive Care Unit with her father, who experienced numerous complications from brain surgery, from which he never recovered. The time spent in hospital made her keenly aware of the lack of awareness for palliative care, as well as health care provider discomfort with discussing wishes for end of life care and reluctance in seeking assistance from palliative care physicians. Tara is passionate about enhancing the health care experience for patients and families, and has a thorough understanding, knowledge and analysis of health care disciplines and the health care sector from working in this field for many years. Her current role in health policy focuses on driving provincial improvements in palliative care, which includes identifying best practice tools and resources to support primary care providers in initiating and engaging in ACP and Goals of Care Discussions. Along with Judith Wahl, Tara is an active participant and member of the HPCO HCC and ACP Community of Practice and Leadership Table.