



**LAW COMMISSION OF ONTARIO
COMMISSION DU DROIT DE L'ONTARIO**

IMPROVING THE LAST STAGES OF LIFE

Call for Research Papers

The Law Commission of Ontario (LCO) is undertaking a project that reviews Ontario's law and policy framework for providing care to persons who are approaching death and services for those who support them, including caregivers, family members, friends and health care providers. A general description of the project, the LCO's mandate and associated resources may be found on the LCO's website at www.lco-cdo.org and we urge applicants to carefully read the information presented there.

From May to September 2015, the LCO conducted preliminary research and consultations in order to understand the overall context in which the law operates and to identify core issues that the project will address. Based on this initial work and our ongoing research, the LCO is now developing a discussion paper that will review and analyse a range of issues and set out questions for public consultation. We expect to release the discussion paper and accompanying materials, including a discussion paper summary, in mid-2016. Together, these documents will form the foundation for dedicated public consultations that the LCO will lead in various locations throughout fall 2016.

As part of the development of the discussion paper, the LCO will fund a number of research papers that will inform our development of options for reform. A list of potential research paper topics, application requirements and terms for funding are set out below.

I. RESEARCH TO BE FUNDED

i. Objectives

The objective of this Call for Research Papers is to obtain expert input on complex issues of law and policy relating to care in the last stages of life. The resulting research will assist the LCO in making reasoned, evidence-based and practical reform recommendations. The Call for Research Papers also aims to create critical debate and promote scholarly work on the subject matters at issue.

The LCO takes a holistic approach to law reform and encourages multidisciplinary research and proposals from research teams. We encourage proposals from experts in relevant disciplines, including law, medicine and the social sciences, and from organizations representing or serving interested communities, such as patients, caregivers, health care providers, older adults and persons with disabilities.

Researchers are encouraged to leverage relevant quantitative or qualitative research that they have already completed or to undertake original quantitative or qualitative research, so long as it is feasible within the timelines set out below.

ii. Research paper topics

The LCO will fund a number of research papers to be determined after considering all of the proposals we receive. We have identified ten potential research paper topics, described below. We will also consider proposals on other topics that would make a demonstrable contribution to our understanding of the issues identified in the description of the project on our website and that would benefit from external, expert knowledge that the LCO might not be able gain otherwise through internal research and consultations.

We encourage proposals that take into account how the issues under consideration may be affected by various aspects of diversity, including age, culture, faith, language, literacy, place of residence (both geographical and by type of care setting), economic status, gender identity and expression, sexual orientation, Aboriginal identity and disability, among others.

Detailed descriptions of the following research paper topics are provided further below:

1. Integrating religious and cultural supports into quality care in the last stages of life: theoretical foundations and practicable models for Ontario's health care system.
2. A rights-based perspective on the delivery of medical aid in dying in Ontario care settings.
3. Balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withholding and withdrawal of life-sustaining treatment.
4. Policies and procedures to facilitate alternative dispute resolution for end-of-life decision-making, including preventative approaches.
5. Understanding the lived experience of individuals, caregivers and family members with Ontario's system for care in the last stages of life and possibilities for enhanced advocacy supports.
6. Managing transitions within and between care settings for individuals, caregivers, family members and health care providers.
7. Challenges and opportunities associated with integrating a palliative approach into services and supports for frail older adults, and persons with chronic and degenerative conditions from the early stages.
8. Informed consent, advance care planning and substitute decision-making: using practice tools to ensure meaningful decision-making in the last stages of life.
9. Challenges for personal support workers in delivering quality care in the last stages of life: understanding their roles, education, training and employment.
10. Addressing law and policy barriers to the provision of appropriate medications for persons living in the community.
11. Other paper topics requiring expert research that would make a demonstrable contribution to the LCO's project.

1. *Integrating religious and cultural supports into quality care in the last stages of life: theoretical foundations and practicable models for Ontario's health care system*

Faith and cultural supports are an accepted element of care for persons who are approaching death, their family members and the broader communities to which they belong. Adherence to beliefs and practices may have strong importance at the end-of-life for a range of issues, including decision-making about personal care and life-sustaining treatments, feelings of comfort and overall well-being. However, the extent to which faith and cultural needs are met through accommodations or other supports and services varies. For instance, facility policies may limit the number of family and community members who can visit a patient at once and traditional practices, such as prayers in the final moments important in many religions, could be overlooked. Given the importance of faith and cultural supports in the last stages of life, the LCO wishes to understand existing needs, challenges and opportunities in this area to inform our consideration of improvements for quality care.

The LCO seeks a research paper that will review and analyze

- **examples of beliefs and practices from different faiths and cultures that are important during the dying process;**
- **the role of faith and cultural supports in providing quality care at the end-of-life and, especially, in preventing, mediating and diffusing conflicts about treatment decisions;**
- **common challenges with integrating faith and cultural supports into quality care;**
- **related accommodations for patients, substitute decision-makers, caregivers, family and community members under the *Charter of Rights and Freedoms* and provincial human rights legislation;**
- **policies to integrate proactive faith and cultural supports into quality care, for instance, educational training for health care providers, faith and cultural counselling and referrals to leaders in the community; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

2. *A rights-based perspective on the delivery of medical aid in dying in Ontario care settings*

Following the Supreme Court of Canada's decision in *Carter v. Canada* (which found *Criminal Code* provisions prohibiting physician-assisted death to be unconstitutional), two expert panels were convened by the federal government, on the one hand, and by the Ministers of Health and Attorneys General for eleven provinces and territories, on the other, in order to consider regulatory options for their jurisdictions.

The LCO is seeking further, detailed expert information on the rights implications of medical aid in dying for patients, caregivers, family members, health care providers and facilities in Ontario. Specifically, the LCO wishes to understand how various rights and principles that have been

developed in the context of other types of care, such as palliative care, could be translated into approaches to medical aid in dying. Examples include the provision of seamless, high quality care and support; equitable access for all Ontarians; and bereavement support for caregivers and family members. To the extent possible, research on this topic will maintain a practical focus on applied models for delivering services that builds on the expert panels' recommendations (once released), government-initiated developments, approaches in comparable jurisdictions and a solid appreciation of Ontario's institutional context.

The LCO seeks a research paper that will review and analyze

- **rights and principles associated with other types of care, such as palliative care, that could be translated into a foundation for rights and principles associated with delivering medical aid in dying;**
 - **challenges affecting vulnerable communities that may face difficulties accessing medical aid in dying based on factors such as place of residence;**
 - **the respective roles of physicians, nurses, facilities, caregivers and others;**
 - **issues relating to conscientious objection that are relevant (although this is not the primary focus of the research paper);**
 - **frameworks in jurisdictions that provide valuable comparators to Ontario; and**
 - **other issues considered to be of significant relevance to a full analysis of this topic.**
3. *Balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withholding and withdrawal of life-sustaining treatment*

The *Health Care Consent Act, 1996* (HCCA) governs Ontario's regime for informed consent, capacity and substitute decision-making for treatment. In *Cuthbertson v. Rasouli*, the Supreme Court of Canada interpreted what the HCCA requires where there are conflicting arguments about who should have the ultimate say in whether to withdraw life-sustaining treatment. However, individuals and organizations within the legal and health care community have expressed that they face challenges applying *Rasouli* to end-of-life decisions about the withdrawal and withholding of treatment in factual circumstances that are not analogous. Furthermore, there are ongoing debates about whether substitute decision-makers or health care providers ought to decide the course of treatment for an incapable person when, in the health care provider's opinion, the treatment is of little or no "beneficial" value.

These debates raise very sensitive but important issues about quality of life, rights to autonomy in decision-making, resource allocation and the security of patients who cannot make end-of-life choices for themselves. A research paper that considers the full spectrum of legal, ethical and clinical aspects about competing interests would make a significant contribution to the LCO's project. The research paper on this topic will draw on the LCO's findings in our separate project on *Legal Capacity, Decision-Making and Guardianship*, in particular, the interim report to be released in January 2016. The LCO also particularly welcomes proposals on this topic that indicate the

applicants will rely on completed or new qualitative or quantitative research on affected stakeholders' perceptions.

The LCO seeks a research paper that will review and analyze

- **existing jurisprudence, legislation and policies in Ontario relating to consent requirements for withholding and withdrawing life-sustaining treatment, including Do-Not-Resuscitate orders;**
- **definitions and the appropriateness of terminology commonly used in this area, such as “non-beneficial treatment”, “medical futility” and “medically inappropriate treatment”;**
- **competing interests of patients, substitute decision-makers, family and health care providers;**
- **mechanisms to ensure that decisions are made in the patient’s best interests;**
- **frameworks in jurisdictions that provide valuable comparators to Ontario, both contrasting and similar; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

➤ For more information on the LCO’s project *Legal Capacity, Decision-Making and Guardianship*, please visit our website: <http://www.lco-cdo.org/en/capacity-guardianship>.

4. *Policies and procedures to facilitate alternative dispute resolution for end-of-life decision-making, including preventative approaches*

Three administrative tribunals adjudicate disputes about care in the last stages of life in Ontario. The Consent and Capacity Board adjudicates disputes about legal capacity and decision-making, including issues surrounding the appropriateness of a substitute decision-maker’s provision of consent for end-of-life treatments. The Health Professions Appeal and Review Board considers regulatory college determinations about matters of professional conduct. The Health Services Appeal and Review Board adjudicates complaints about eligibility for home and community services that have been dismissed in Community Care Access Centres review processes.

This research paper topic is intended to address alternative dispute resolution mechanisms that might be used to simplify and increase access to conflict management at an early stage, for instance through standardized procedures that could be integrated into health care facilities’ policies. Our definition of alternative dispute resolution in this context is broad; it includes mechanisms that can be accessed once a conflict has occurred as well as measures that could be used to avert disputes, such as the provision of information, advocacy supports and informal counselling. The research paper on this topic should address the types of disputes that are known to have been adjudicated at the administrative tribunals mentioned above and any others that are relevant.

The LCO seeks a research paper that will review and analyze

- **possible benefits of alternative dispute resolution for end-of-life decision-making in Ontario, including preventative measures;**

- **existing policies and practices employed in relevant care settings, including challenges and opportunities;**
- **practicable models for alternative dispute resolution in relevant care settings; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

5. *Understanding the lived experience of individuals, caregivers and family members with Ontario's system for care in the last stages of life and possibilities for enhanced advocacy supports*

Ontario's system for care in the last stages of life is complex. Individuals who are approaching death may find themselves with varying levels of services depending on factors including their geographical location, access to a family physician with knowledge about palliative care and admission to a hospital with a specialized consultation team. Navigating the system can be challenging for such individuals as well as for the caregivers and family members who assist them. They might not know who or what to ask about issues that affect them. Furthermore, everyday impediments such as restrictions on visiting hours and physical environments could frustrate other efforts to deliver quality medical services.

This research paper topic is intended to capture the perspectives of persons who directly interact with Ontario's system for care in the last stages of life as users, including the challenges they experience and possible solutions. As a result, successful applicants will be required to gather qualitative information that summarizes diverse stakeholder viewpoints, either from existing sources or through new research. The subject matter of this research paper differs from that described in topic #3, insofar as it concerns experiences navigating the health care system and advocacy supports, rather than decision-making laws about the withdrawal and withholding of treatment. However, one aspect of this research paper could also examine "transitions" as discussed in the research topic immediately below (topic #6).

The LCO seeks a research paper that will review and analyze

- **how individuals, caregivers and family members perceive Ontario's law and policies related to care in the last stages of life;**
- **existing barriers to and supports for navigating Ontario's system for care in the last stages of life, taking into account social determinants such as age, disability, lack of legal capacity and income, among others;**
- **a range of options for improving access to information, rights advice and system navigation; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

6. *Managing transitions within and between care settings for individuals, caregivers, family members and health care providers*

Care in the last stages of life is provided in a number of settings, which include hospital departments, residential hospices, long-term care homes, private homes and community centres.

Services in these different locations are funded and managed separately by the Ministry of Health and Long-Term Care, Local Health Integration Networks (LHINs) and other delegated organizations, and they may be regulated under different statutes. Moreover, services in the community tend to be arranged through separate services agencies that employ nurses, personal support workers and other health care providers who come and go. As a result, individuals, caregivers and family members may face difficulties understanding and proceeding through transitions from one setting to another. Aside from those who are directly affected, health care and service providers may have concerns about their own involvement in transitions in terms of education and training, and their respective obligations to assist. This research paper will consider potential solutions to ease transitions within and between care settings, taking into account Ontario's law and policy framework and possible developments in the institutional context in the near future.

The LCO seeks a research paper that will review and analyze

- **core transitions within and across care settings, including hospital (emergency departments, intensive care units, complex continuing care, palliative care units), home and community, long-term care and residential hospice;**
- **existing law and policy barriers to and supports for seamless transitions;**
- **the respective roles of health care and service providers in facilitating seamless transitions;**
- **a range of options for improving transitions, possibly including simplification of the law, policies or processes; clear assignment of responsibility to providers; provision of additional supports; barrier removal and other options; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

7. Challenges and opportunities associated with integrating a palliative approach into services and supports for frail older adults, and persons with chronic and degenerative conditions from the early stages.

Palliative care strives to help all individuals, families and caregivers address physical, psychological, social, spiritual and practical issues arising in the dying process through a range of supports and services. The delivery of palliative care is based on a philosophy of care, which is often referred to as a "palliative approach". It is not possible to deliver the same level and types of services and supports to all people who have life-limiting conditions because each individual has a different illness trajectory and unique needs. Moreover, care settings are equipped to provide relevant services and supports to varying extents.

This research paper topic considers how the palliative approach could be integrated into services and supports for persons whose illness trajectory may be less certain or last longer than those who might be eligible for specialized palliative care programs in Ontario. In particular, the LCO is interested in understanding how older adults with frailty might benefit from care as well as persons with chronic and degenerative conditions that are not in the advanced stages. How could these persons be identified effectively? What types of care could they benefit from? What language could be helpful to discuss their options?

The LCO seeks a research paper that will review and analyze

- **challenges with and opportunities for identifying persons who could benefit from a palliative approach, including frail older adults and persons with chronic and degenerative conditions that are not at an advanced stage;**
- **practicable law and policy options for delivering care to such persons in a range of settings, including long-term care homes and in the community;**
- **law and policy frameworks in jurisdictions that provide valuable comparators to Ontario; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

8. *Informed consent, advance care planning and substitute decision-making: using practice tools to ensure meaningful decision-making in the last stages of life*

Illness and medications can diminish the capacity to make decisions that affect a person's level of suffering, life-expectancy and overall well-being in the last stages of life. Near the end of life, especially, the legal framework for informed consent, advance care planning and substitute decision-making is a constant concern in the minds of all interested parties. The LCO's project on legal capacity and decision-making reviews the *Substitute Decisions Act, 1992* and *Health Care Consent Act, 1996*. Furthermore, the LCO commissioned a research paper in the context of that project that thoroughly reviewed health care consent and advance care planning in Ontario, including through a literature review and survey of institutional policies and practices.

This new project will build on our findings in the earlier one as well as the previously commissioned research paper. The objective of this research paper is to consider possible improvements to policies, toolkits and forms ("practice tools") that are used for decision-making in the last stages of life in order to ensure consistency with the legislative framework and meaningful decision-making. This research paper must not duplicate work that has already been completed in the LCO's other project. It should be narrowly focused on assessing whether the creation of standardized practice tools would or would not be beneficial in this context; which organizations would be responsible for any such practice tools, including government, regulatory colleges, Local Health Integration Networks and others; what any "family" or "package" of such practice tools would be comprised of and how they could be implemented in Ontario's diverse care settings. This research paper will also need to consider linkages between informed consent, advance care planning and substitute decision-making and "goals of care" plans as well as any ongoing initiatives in this area in Ontario.

The LCO seeks a research paper that will review and analyze

- **challenges with existing practice tools being used in Ontario, beyond what is reported in the LCO's other project, if any;**
- **whether the creation of standardized policies, toolkits and forms for decision-making would or would not be beneficial to ensuring consistency with and the implementation of the *Substitute Decisions Act, 1992* and *Health Care Consent Act, 1996*;**

- what the contents of any possible family of practice tools could be with reference to both health care consent and advance care planning;
- which governmental or non-governmental organizations could be responsible for any practice tools and in what ways;
- how any practice tools could be implemented in care settings, including hospitals, home and community, residential hospice and long term-care homes;
- intersections with any possible practice tools and goals of care plans; and
- other issues considered to be of significant relevance to a full analysis of this topic.

➤ For more information on the LCO's project *Legal Capacity, Decision-Making and Guardianship*, including the commissioned paper referred to above, please visit our website: <http://www.lco-cdo.org/en/capacity-guardianship>.

9. *Challenges for personal support workers in delivering quality care in the last stages of life: understanding their roles, education, training and employment*

Personal support workers (PSWs) provide essential assistance to persons residing in long-term care and at home. They support individuals with a range of daily living activities such as bathing, feeding and dressing, and they may provide respite for caregivers. In Ontario, PSWs are not regulated professionals. There are professional associations that disseminate best practices to PSWs, deliver training and maintain registries on a voluntary basis. However, the state of education, training, accountability and employment context of PSWs who engage in palliative and end-of-life care is unknown. Notwithstanding their important contributions, PSWs may face many challenges in the course of their work, such as coordinating with substitute decision-makers when a person is incapable, caring for persons who have advanced dementia and dealing with employment-related tensions that may arise with individuals, families and employers, among other issues. A review of the role of PSWs in this area, the challenges they face, current practices and options for reform would add considerable value to the LCO's project.

The LCO seeks a research paper that will review and analyze

- the role of PSWs in delivering care in the last stages of life in relevant care settings, including home and community, residential hospice and long term-care homes;
- current education and training for PSWs in palliative and end-of-life care, including issues surrounding decision-making, and frameworks to ensure competency standards;
- employment-related concerns that commonly arise in this context, including avenues of recourse for PSWs;
- challenges and opportunities for improved education, training, accountability and employment-related issues in this area; and
- other issues considered to be of significant relevance to a full analysis of this topic.

10. Addressing law and policy barriers to the provision of appropriate medications for persons living in the community

Medications for pain and symptom management are covered under OHIP when patients are in hospital. Outside hospital, programs such as the Ontario Drug Benefit program cover designated medications. Palliative care medications are available to patients with terminal illness through special procedures for facilitated access. However, there may be barriers to receiving these medications due to the unavailability of physicians after hours, prohibitions against pain medications in care settings, such as group homes, and ineligibility for provincial health insurance, among other factors. This research paper topic is intended to consider barriers to prescribing, administering and insuring appropriate medications for persons living in the community. It should consider persons living in private homes as well as in long-term care, shelters, group homes, mental health facilities and on the streets.

The LCO seeks a research paper that will review and analyze

- **the regulation of physicians and nurses' prescribing and administering rights for palliative care medications in Ontario;**
- **barriers that individuals experience when seeking to access palliative care medications outside hospital, if any, such as policies in care settings, insurance coverage and application delays;**
- **practicable options to address barriers and improve access to palliative care medications; and**
- **other issues considered to be of significant relevance to a full analysis of this topic.**

11. Other paper topics requiring expert research that would make a demonstrable contribution to the LCO's project.

The LCO will consider proposals on topics that have not been identified in this Call for Research Papers that would make a demonstrable contribution to our understanding of the issues identified in the description of the project on our website and that would benefit from external, expert knowledge that the LCO might not be able gain otherwise through internal research and consultations.

II. SUBMISSION PROCESS

i. Selection criteria

Proposals will be evaluated on the degree to which they achieve the following:

- Further the objectives of this Call for Research Papers and of the project.
- Maintain coherence with the mission of the LCO.
- Demonstrate professional qualifications and expertise in the area to be studied.
- Demonstrate a sound analytical framework and research methodology.

ii. Format of proposals

Submitted research proposals must contain the following materials:

1. A statement outlining the proposed research, how the research would support the objectives of the project as outlined in this Call for Research Papers, and the scope and the type of work envisioned.
2. A work plan that outlines
 - the proposed research methodology, including any proposed original quantitative or qualitative research;
 - the use of any relevant quantitative or qualitative research already undertaken by the researcher;
 - the steps required to complete the assignment on the dates listed below; and
 - an estimate of the resources required to complete the assignment.
3. A cover letter detailing the applicants' qualifications, including their experience with past research on issues raised in the proposal or analogous issues, and the reasons why the applicants are interested in undertaking the research.
4. A Curriculum Vitae for each principal researcher.

PLEASE NOTE THAT INCOMPLETE PROPOSALS MAY NOT BE CONSIDERED.

iii. Proposal deadlines

Research proposals must be submitted by midnight on **January 22, 2016**. Proposals received after this date will not be considered. Authors of successful proposals will be notified by **February 5, 2016**.

iv. Questions about proposals

Questions about proposals should be submitted at the latest by **January 15, 2016**. The LCO will post responses to such questions on our website as quickly as possible. We will ensure that identifying information is kept confidential to protect the applicants' privacy. Questions must be directly addressed to the project head, Sarah Mason-Case, at smason-case@lco-cdo.org or (416) 650-8232.

v. Contact Information

Please forward your proposals to the attention of the project head, Sarah Mason-Case, through one of the means indicated below:

Mail: Sarah Mason-Case
Research Lawyer
Law Commission of Ontario
2032 Ignat Kaneff Building
Osgoode Hall Law School, York University
4700 Keele St., Toronto, ON M3J 1P3

Fax: (416) 650-8418

E-mail: LawCommission@lco-cdo.org

III. TERMS OF THE CALL FOR RESEARCH PAPERS

The Terms of the Call for Research Papers are as follows:

i. Budget guidelines

The selected applicants will be paid a total of \$15,000 (including GST) for the paper, as allocated to each stage of the paper, when completed in accordance with the agreement as determined by the LCO.

ii. Timelines and deliverables

Applicants who are successful in contracting to provide a research paper will be required to complete (a) a detailed outline, (b) an interim research paper and (c) a final research paper (the “Deliverables”). The interim research paper must be a substantially complete version of the final research paper and subject only to slight revisions. The interim research paper must be formatted and include citations in accordance with the LCO’s formatting policy. The interim research paper and the final research paper must assess and analyze all of the issues described under the appropriate paper topic in section I above, “Research to be Funded”. The LCO reserves the right to determine whether the paper has met the requirements at each stage as explained above and is not obligated to provide payment if those requirements are not met and to terminate the agreement. The LCO will not take this step until after a discussion with the researcher.

Selected applicants must provide the LCO with the Deliverables in accordance with the agreement by these dates:

DEADLINE	DELIVERABLES	PAYMENT
March 15, 2016	Detailed outline	\$2,500
May 15, 2016	Interim research paper	\$5,000
June 15, 2016	Final paper	\$7,500

Compliance with the above deadlines is of critical importance to the LCO. In the event that a deadline is not met, the LCO may choose to terminate the agreement. Where the agreement is terminated, the LCO is not obligated to provide payment for any Deliverable that has not been provided to the LCO at the time of termination.

iii. Copyright

Contract researchers are expected to assign copyright to the LCO, but will retain moral rights to their work. Contract researchers will be given credit for their work when the LCO publishes materials resulting from their work in any format. Contract researchers may write separate materials, such as articles, arising out of their research for the LCO with acknowledgement that the work was originally carried out for the LCO. Applicants are encouraged to review the LCO's *Policy on Copyright & Attribution*, available on the LCO website at <http://www.lco-cdo.org/en/copyright-attribution-policy>.