

Last Stages of Life – Indigenous Engagement Advisory Group Terms of Reference

November 2018

Overview of the Last Stages of Life Project

The Law Commission of Ontario (LCO) is leading an independent study that considers how the law shapes the rights, choices, and quality of life for persons who are dying and those who support them. The "last stages of life" is the broad and inclusive term used in this project ("the project") to include experiences related to palliative care, end-of-life care, and medical assistance in dying.

Per the project scope as approved by LCO's Board of Directors, the project seeks to address the experiences of everyone involved in the dying process, including: individuals; caregivers and other family and friends; cultural, religious and spiritual communities; health care institutions and professionals; government; other professionals; and community organizations.

Purpose of an Indigenous Engagement Process

The use of the term Indigenous adopts the United Declaration on the Rights of Indigenous Peoples use of the term which is not defined. The Indigenous representatives of the UN Working Group 1996 stated, "We categorically reject any attempts that Governments define Indigenous Peoples" and instead endorsed the concept of "indigenous" which acknowledges the right of Indigenous peoples to name themselves.

Indigenous represents a broad term that encompasses First Nation, Métis and Inuit and includes status and non-status. The Indigenous Engagement will always respect and recognize the right of each community to name themselves.

The Indigenous Engagement process with LCO acknowledges that Indigenous worldview, laws, practices, geography, socio-economic factors and colonialism will inform a diversity of experiences of First Nation, Métis and Inuit people and that Canadian health care laws may or may not be accessible, considered or known.

We further acknowledge that questions of law reform are questions of reconciliation in relation to historical and continuing experiences of colonialism and trauma.

A primary purpose of the Indigenous Engagement is to ensure First Nation, Métis and Inuit views are represented and inform the Last Stages of Life project around Indigenous laws and health practices as well as identify gaps or omissions in Indigenous experiences with the health care system specific to end of life care. The Indigenous Engagement findings will inform a report to the Ministry of the Attorney General. The report would encompass a diversity of First Nations, Métis and Inuit laws and health practices for the purpose of making intercultural space that would allow for FNMI laws to apply.

Mandate of the Indigenous Engagement Advisory Group

The mandate of the Indigenous Engagement Advisory Group (IEAG) is to provide expert advice to the LCO in the design, development, facilitation, and oversight of an Indigenous engagement process related to the last stages of life. The IEAG will work with the Indigenous Engagement Lead and Principal Lead of the Last Stages of Life project and advise on the analysis of research findings, including the identification and recommendation of any potential law reforms and their prioritization.

Goals of the Indigenous Engagement

The goal of the Indigenous Engagement is to inform The Last Stages of Life project (the project) by looking beyond the western legal order to First Nation, Métis and Inuit laws in order to learn about the diversity of Indigenous laws and practices; identify gaps and omissions within western law which would then inform Indigenous recommendations that would allow for the creation of space within existing laws and/or new laws.

The goals of the Indigenous Engagement are to:

- Design and facilitate a meaningful process to engage Indigenous communities in discussion about these issues
- Analyze the findings of the engagement process in relation to law reform
- Research, develop and release public education materials which identify and discuss First Nation, Métis and Inuit experiences, issues, and thinking around how Indigenous and western laws shape the last stages of life for Indigenous peoples

Outcomes of Indigenous Engagement

Enhanced knowledge and understanding of Last Stages of Life care from an Indigenous perspective will inform potential Indigenous recommendations for law and policy reform. The Indigenous Engagement findings will inform a public report to the Minister of Attorney General. The report would encompass a diversity of First Nations, Métis and Inuit laws and health practices for the purpose of making intercultural space that would allow for First Nation, Métis and Inuit laws to apply.

The LCO acknowledges that Indigenous laws around end of life care may be sacred and belong to the community and as such LCO would only share what is permissible and agreed upon.

The Indigenous Engagement process will follow up with each Indigenous community, organization or individual whom contributed knowledge during the Engagement process.

On the advice of the IEAG, the Indigenous Engagement will be led by an Indigenous lawyer and the Indigenous Engagement Lead will seek to ensure First Nation, Métis and Inuit perspectives are reflected. The Indigenous Engagement will be guided by LCO values and mandate and will be independent, consultative, balanced, practically oriented, and guided by public interest values.

Role of the Indigenous Engagement Advisory Group

IEAG members will provide the LCO with recommendations regarding:

- Membership of the IEAG to ensure representative participation from First Nation, Métis and Inuit
- The progress and identification of issues being addressed by the Indigenous Engagement
- The development of outreach, communication and engagement strategies
- All materials generated in relation to the Indigenous Engagement
- Identification of communities, groups, individuals, experts, and potential partners with whom to engage
- Review of analysis of Indigenous Engagement and research findings, including the identification and recommendation of any potential law reforms and their prioritization
- IEAG participation in Indigenous Engagement sessions, optional
- Monthly meetings to receive updates on the Indigenous Engagement, in person or by conference call
- To maintain confidentiality on draft documents tabled for discussion

Role of the ICO

The LCO is the secretariat and administrator for the project. The LCO team for the Indigenous Engagement includes: Ryan Fritsch, Principal Lead for the Last Stages of Life project, Cassandra Baars,

Indigenous Engagement Lead and Nye Thomas, Executive Director of the LCO, is the project director.

Funding for the Indigenous Engagement is being provided by the LCO and will collaborate with other funders/supporters if it is appropriate to do so. Indigenous Engagement funds will be administered by the LCO.

The LCO will:

- Provide required project management resources including budgeting, scheduling, and communications
- Provide the IEAG with necessary resources, including compensation for expenses incurred, see attached Project Advisory Group Reimbursement Guidelines
- Conduct research and develop all Indigenous Engagement materials in conjunction with the Indigenous Engagement Lead
- Engage the IEAG in analysis of engagement findings and potential law reform initiatives
- Principal Lead will draft report and recommendations and the Indigenous Engagement Lead will assist with suggested edits, content and format
- Present draft recommendations to Indigenous Engagement Advisory Group for review and comment

Role of the Indigenous Engagement Lead

To provide a roadmap for the key components of an Indigenous Engagement process with Indigenous community organizations, Indigenous health professionals, Indigenous communities, Indigenous Elders and youth in order to assist Law Commission of Ontario (LCO) to learn about First Nation, Métis and Inuit experiences with the regards to palliative care, end of life care and medical assistance in dying.

The Indigenous Engagement Lead will:

- Develop and implement Indigenous Engagement strategy within LCO's Last Stages of Life project, see attached draft Indigenous Engagement plan
- Be the primary point of contact for the Indigenous Engagement, the Principal Lead will oversee the process to ensure LCO administrative protocols are followed and is a resource as subject matter expert on the project
- Collaborate with the Principal Lead of the Last Stages of Life project on the work plan, materials, analysis and eventual recommendations, see attached draft work plan
- Compile a preliminary list of names and organizations from existing, referred and Indigenous Engagement Lead contacts and will ensure representation by geographical location; by First Nation, Métis and Inuit; by Elder and Traditional Knowledge Keepers; by youth and by all genders.

- Determine primary key contacts for initial outreach
- Develop in collaboration with the Principal Lead a broad format for Engagement sessions that allows for open, safe, inclusive engagement on Indigenous health and wellness laws and practices
- Host and lead engagement sessions, hosting all events means that LCO will cover space fees, if any, catering, Elder/Traditional Knowledge Keeper honorarium, thank you gifts for participants
- Seek LCO approval for each engagement session prior to initiating external invitations
- Collaborate with Principal Lead and report incremental results and updates to the Indigenous Engagement Advisory Group for review and comment
- Collaborate with the Principal Lead and follow LCO protocols on any materials for use in engagement sessions, any public facing documents or public statements.
- Summarize results of Engagement sessions, collaborate with the Principal Lead for analysis and present to Indigenous Engagement Advisory Group for review and comment
- Collaborate with Principal Lead with suggested edits, content and format during drafting of the Indigenous Engagement final report and recommendations
- Will meet timelines of workplan

Communications and Public Outreach

The Indigenous Engagement team will develop and distribute background engagement materials to facilitate discussion and engagement on the issues. Materials may include plain language materials for use within eventual engagement sessions and communications materials generally related to the LSL project generally and the purpose and scope of the Indigenous Engagement.

A webpage will be developed to complement public engagement and distribution of any materials. The Indigenous Engagement Advisory Group will have an opportunity to review and advise on any materials developed.

Relationship to Other Initiatives

Many organizations and individuals have undertaken significant work regarding the last stages of life in Indigenous communities in Ontario and elsewhere. The Indigenous Engagement does not want to replicate those initiatives and will work cooperatively with researchers, stakeholders and other organizations to build on current research/policy initiatives to ensure limited resources are used most effectively.