Quebec’s proposed legislation to allow “medical aid in dying” to incurably ill and suffering patients also contains measures that would force more oversight of the province’s palliative-care regime, say medical experts.

While a plan to allow doctors to administer life-ending medication is by far the most high-profile and controversial element of Bill 52, An Act Respecting End of Life Care, it also proposes a new provincial commission to oversee “all matters relating to end-of-life care.” The commission would impose new requirements on hospitals and other facilities to report formally on their practices of treating patients at the end of their lives.

As it stands, hospitals in Quebec and the rest of Canada often offer palliative sedation to ease pain and suffering as part of end-of-life care. In extreme cases, doctors use “terminal sedation,” in which patients are medicated into unconsciousness and deprived of artificial nutrition to expedite imminent death.

There are currently no concrete, uniform rules governing palliative terminal sedation, says Jocelyn Downie, a professor who specializes in health, law and ethics at Dalhousie University, Halifax, Nova Scotia. As a result, jurisdictions, hospitals and even doctors often determine their own practices, she says.

This “black hole … is a grave concern. We just don’t know how much it is happening,” Downie says. Without clear guidelines or reporting, there is no way of knowing when and why terminal sedation is provided. “It might well be happening in circumstances in which many people think it would be inappropriate or indefensible. But we simply don’t know.”

Dr. Marcel Boisvert, a retired palliative care physician, says he was involved in terminal sedation at least six times during his 18 years at Montréal’s Royal Victoria Hospital. No clear rules governed the process, he says, which was handled on a case-by-case basis. Deciding whether terminal sedation is the best option is often a judgment call made by doctors, after consulting with patients and families.

Boisvert believes euthanasia is more humane because patients can live for days or weeks while terminally sedated, which he says is agonizing for family members keeping a bedside vigil.

“This is terrible for the family,” Boisvert says. “They don’t want to leave the room even to go to the bathroom.”

Quebec’s proposed legislation would make palliative care treatment more transparent in the province, say Boisvert and Downie, who both strongly support the bill.
The legislation may actually lead to improved palliative care, as has happened in other jurisdictions that permit euthanasia and/or doctor-assisted suicide, says Downie. “When you bring these practices out into the open … you have full conversations about the full spectrum of end-of-life care and [how to] do pain management better,” she says.

But Dr. Gerald van Gurp, who provides palliative home care in Montréal, contends the opposite is true. “In the jurisdictions where euthanasia and physician-assisted suicide have become legal, there has been less of an incentive to develop high quality palliative care. It’s kind of an inverse relationship.”

“The more physicians know about palliative care, the less interested they are in euthanasia,” he says, adding that improving publicly funded home care to ease dying patients’ pain and suffering would negate the need for euthanasia. In his three decades of providing palliative care, he says he has never encountered a patient whose pain could not be relieved by sedatives and around-the-clock care by doctors, nurses and other medical professionals.

Quebec’s foray into medically assisted death began in 2009, when the National Assembly struck a commission to study the practice. Its 24 recommendations called for a comprehensive “dying with dignity” law. Following public hearings across the province in 2010 and 2011, a second report was commissioned from legal experts. That report, released in January 2013, elaborated on the commission’s recommendations and called on the Quebec government to create clear legislation on both assisted suicide and euthanasia.

It cited a 2012 Supreme Court of British Columbia ruling by Madame Justice Lynn Smith on assisted suicide. The 375-page ruling examined practices in jurisdictions that have legalized assisted suicide. Smith rejected the argument, voiced by opponents, that assisted suicide erodes palliative care or preys on vulnerable patients who fear they may be pressured into agreeing to be injected with lethal substances. Her ruling, which found an absolute ban on assisted suicide unconstitutional, is under appeal.

Four American states — Oregon, Washington, Montana and Vermont — permit assisted suicide, in which doctors can prescribe life-ending medication under strict conditions. In Europe, the Netherlands, Belgium and Luxembourg have legalized both assisted suicide and euthanasia, in which doctors administer the medication. Switzerland allows assisted suicide, but bans euthanasia.

Quebec’s proposal does not permit doctor-assisted suicide, this means that physicians provide the life-ending medication to patients who meet the stringent criteria, but the patients must self-administer that medication.

If passed, the Quebec law permitting medically assisted death will be the first in Canada. It means that patients suffering from “constant and unbearable physical and psychological pain” from an “incurable serious illness” that is “at an advanced stage of irreversible decline” will be allowed to decide when to die. They would have to consent in writing to terminal sedation and two doctors would have to agree that a patient’s condition qualifies for life-ending medication. Doctors and hospitals would have to track the administration of that sedation.
Physicians could refuse to carry out a patient’s request for the medication, but they would be obliged to inform a supervisor so another doctor could step in.

The Quebec College of Physicians backs the bill, and is helping the provincial government devise a euthanasia protocol, including the appropriate medication to use. However, a group of about 500 of Quebec’s 21,000 physicians, sees no reason to change the legal status quo.

“I don’t think the solution is to kill people, the solution is to improve end-of-life care,” says Dr. Catherine Ferrier, spokesperson for Total Refusal of Euthanasia in Montréal.

She says she is particularly concerned about “the risk of vulnerable people being euthanized who didn’t ask for it.” As a doctor who cares for geriatric patients, Ferrier says she sees a lot of elder abuse in which patients are maltreated by relatives.

Also, the proposed legislation is worded so broadly that it could apply to almost anyone, says Ferrier. She is concerned that people with psychiatric illnesses and dementia are not specifically excluded.

Véronique Hivon, Quebec minister for social services and youth protection, has said she wants to start public hearings on the specifics of the bill this fall. — Janice Tibbetts, Ottawa, Ont.