CANADIAN PROVINCIAL/TERRITORIAL
EXPERT ADVISORY GROUP ON PHYSICIAN-ASSISTED DYING

WRITTEN STAKEHOLDER SUBMISSION FORM

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BACKGROUND

In February 2015, the Supreme Court of Canada struck down the federal law prohibiting physician-assisted dying (PAD). The ruling applies to a competent adult who:

- Clearly consents to the termination of life; and
- Has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition

The court gave governments one year to consider the development of new laws and practices for physician-assisted dying.

In July 2015, the federal government established an external panel to inform its legislative response to the Supreme Court of Canada's decision. The primary focus of the Federal Expert Panel's work is to provide advice to the federal government on possible amendments to the Criminal Code. In August 2015, eleven provinces and territories established the Provincial/Territorial Expert Advisory Group on Physician-Assisted Dying (the "Advisory Group").

As provinces and territories have the primary responsibility for health care, including regulating physicians and health care institutions, provincial and territorial governments must consider whether regulatory or other changes are needed over the coming months in response to the Supreme Court's decision. The Advisory Group will provide advice on the development of laws, policies, practices and safeguards for provinces and territories to consider in advance of physician-assisted dying becoming legal in Canada.

Your organization's input and feedback will be considered as part of the Advisory Group's deliberations.

INSTRUCTIONS

The Advisory Group is seeking input on the following questions. Your organization's responses will be used by the Advisory Group to inform its advice to the provincial and territorial governments on physician-assisted dying, with a focus on the needs of patients and their families as well as health institutions and regulatory bodies.

Please answer all questions relevant to your organization's interests. **If your organization does not have a position or opinion on a particular issue, please feel free to leave that section blank.** Please limit your response to each question to 1000 characters (or approximately 200 words). If your organization has developed specific guidance (e.g., policy, guidelines) for its staff or members related to the implementation of PAD, you may attach it to your reply email. Please send the completed template and attachment to PADadvisorygroup@ontario.ca by **September 24, 2015**.

Please note that all information collected by the Advisory Group is governed by Ontario's *Freedom of Information and Protection of Privacy Act* and may be subject to disclosure in accordance with that Act. In addition, comments or documents provided to the Advisory Group may be shared with provinces and territories participating in the work of the Advisory Group and will be treated as public information that may be used and disclosed by the Advisory Group without the consent of the author, or the organization on whose behalf the submission is made. As such, please ensure that you do not include any personal information about identifiable individuals in your responses to this template.

The information collected will be considered by the Advisory Group in developing recommendations for provinces and territories to consider as they develop their responses to the Supreme Court's decision on physician-assisted dying. If you have any questions about how the Advisory Group will collect, use and disclose the information that you are providing, please contact Alicia Neufeld at Alicia.Neufeld@ontario.ca.

QUESTIONS	FEEDBACK
GENERAL	
What are your organization's thoughts on the Supreme Court of Canada's decision in *Carter v. Canada (Attorney General)?*	It was the BCCLA that brought the case forward, and we were elated with our victory. Given character limits, in the answers that follow: BCCLA = British Columbia Civil Liberties Association PAD = physician-assisted dying SCC = Supreme Court of Canada Province / provincial = province and territory / provincial and territorial DWD = Dying With Dignity Canada Paragraph citations (e.g.: "para. 106") are references to the SCC's decision in Carter v. Canada, [2015] 1 SCR 331. Many of the questions here were canvassed in detail, including review of a massive body of Canadian and international evidence, in the SCC and trial decisions. We strenuously suggest that the Advisory Group review those decisions in detail.

In general, should provinces and territories develop new legislation or regulations to govern the provision of physician-assisted dying (PAD) or should the regulation of PAD be left to regulatory bodies (e.g., professional colleges) and/or individual physicians and patients?	Possibly, to the extent that provincial legislation can help to ensure equitable access to PAD across and within Canadian jurisdictions, and consistent standards. For example, ensuring reasonable access in various regions of a province may be best provided for by legislation. In addition, the treatment of PAD by life insurance providers could require clarifying legislation. In general, we believe that PAD can and should be regulated according to the well-established standards of informed consent that already govern medical treatment and end-of-life decision-making in the medical system. These standards are considered sufficient for all other comparable end of life decisions. It should be noted that the SCC's ruling did not require Parliament or the legislatures to enact legislation. The Court said that they could enact laws, "should they so choose". If no action is taken by Parliament or the legislatures, there will not be a regulatory or legal vacuum and PAD will be governed by the existing standards of the medical profession.
ELIGIBILITY CRITERIA	
In the Supreme Court of Canada's decision, it was determined that, in certain circumstances, a "competent adult" must not be prohibited from accessing PAD. • **What should the definition of "adult" be?** • **Should the competency requirement apply at the time of request for PAD or at the time of provision of the assistance, or both?** *See Appendix 1 for additional information.*	An adult is someone who is aged 18 or older. The SCC was clear that an individual must be competent at the time that they make the request. The SCC set out the minimum entitlement to PAD by invalidating the criminal ban on the practice. However, nothing stops legislatures from going further. The judgment does not require that an individual be competent when the assistance is provided, so long as they clearly consent. BCCLA thinks that physicians should be able to act on advance directives requesting assistance in dying made by patients when they were capable. We see no reason why a person, who is competent, cannot make a decision now for themselves later, when they may no longer be competent or no longer able to communicate. Advance directives in respect of PAD should be respected just as they are for other forms of medical decision-making.

The Supreme Court of Canada’s decision limits PAD to those who have a “grievous and irremediable medical condition”. • **What does “grievous and irremediable medical condition” mean to your organization?** • **Should the term “grievous and irremediable medical condition” be defined in the provincial/territorial legislation or regulation?** • **Should specific medical conditions be defined in law or should it be determined in each case by the patient and their physician? If the medical conditions should be defined in law, what medical conditions should be included?** *See Appendix 2 for additional information.*	"Grievous" is a term already understood in the Criminal Code, where it is interpreted to mean serious and non-trivial. No further definition is required, as demonstrated by the fact that this definition has been shown to work well in the criminal context. Irremediable means that the condition may not be relieved to an acceptable level, for the individual, by any treatment that is acceptable to that individual. We do not think these terms should be defined in legislation or regulations. We oppose defining specific medical conditions to which PAD would apply. Whether an illness qualifies must be determined by a patient and doctor together, considering the patient's circumstances. Defining a list risks leaving out people who are constitutionally-entitled to PAD, and will result in complication, exclusion from access, and likely, further costly and unnecessary legal challenges.
PROCEDURAL SAFEGUARDS TO ENSURE ELIGIBILITY CRITERIA ARE MET	
The Supreme Court of Canada’s decision limits PAD to a competent adult person who “clearly consents to the termination of life”. • **What processes should be put in place to ensure that the consent to PAD is informed? (e.g., what information should have to be provided to the patient? Who should provide the information?)** *See Appendix 3 for additional information.*	Physician-assisted dying can and should be treated like other medical decisions, and be governed by the established norms of informed consent law, which has shown itself to be perfectly adequate as a framework for life-and-death medical decisions. We adopt DWD's answer here. Physicians are required to provide information about PAD according to the established norms of informed consent law. This means providing full information about potential treatments, including PAD.

What processes should be put in place to ensure that the consent to PAD is voluntary?	The SCC cited the trial judge's finding that "it was feasible for properly qualified and experienced physicians to reliably assess patient competence and voluntariness, and that coercion, undue influence and ambivalence could all be reliably assessed as part of that process. In reaching this conclusion, she particularly relied on the application of the informed consent standard in other medical decision-making in Canada, including end-of-life decision-making. [...] As to the risk of vulnerable populations (such as the elderly and disabled), the trial judge found that there was no evidence from permissive jurisdictions that people with disabilities are at heightened risk of accessing PAD. [...] The trial judge found there was no evidence of inordinate impact on socially vulnerable populations in the permissive jurisdictions." [paras. 106-107]
What processes should be put in place to ensure that the person requesting PAD is competent? For example: • **Who should conduct the competency assessment(s)?** • **Should an assessment by a psychiatrist or psychologist be required in any or all cases? If some, which ones?)**	Doctors routinely assess competency, and such assessments for PAD need not differ from the routine assessments made for other end-of-life decisions. The SCC summarized the evidence: "Based on the evidence regarding assessment processes in comparable end-of-life medical decision-making in Canada, the trial judge concluded that vulnerability can be assessed on an individual basis, using the procedures that physicians apply in their assessment of informed consent and decisional capacity in the context of medical decision-making more generally." [para 115] Where a physician is uncertain that a patient fully understands and appreciates the nature and consequences of the decision to seek PAD, there could be a specialized capacity assessment, consistent with practice for other treatments. This should not be a requirement for all PAD requests, as this would be an unduly onerous barrier to access.

How many physicians should be required to confirm that the eligibility criteria have been met? Must they be from any particular specialities? Must they be independent of one another? If so, what should be the definition of independent for these purposes?	It is needlessly bureaucratic and a departure from the normal standards of consent around end-of-life decision-making to require a second opinion. There is no evidence to support such a requirement. As noted by the SCC at paras 106-107, physicians can assess competence and voluntariness, and the same applies for a determination of whether the eligibility criteria are met. Normal medical standards include the option of physicians to seek consultation from other physicians as necessary to assist with patient care. This should not be imposed as a requirement because it would add an additional step that is not necessary, based on the evidence, in each case. When this is done, the other doctor should be independent, meaning that the physicians are not in a direct supervisory relationship with each other.
Should a waiting period (sometimes called a "cooling off period") be established between the request and the provision of PAD? If so, how long should the waiting period be? Should the waiting period vary based on the medical condition?	The SCC decision does not require a waiting period. Physicians should have the right to use their own judgment, as they do in all cases in which a patient exercises informed consent in respect of an end-of-life decision. If any waiting period is adopted, it should by in the form of a guideline only, preserving the physician's right to exercise their judgment to move more expeditiously in cases that do not fall within the circumstances contemplated by a guideline.

What should be the formal requirements for a patient's request for PAD? (e.g., should requests be written or can they be oral? Should witnesses be required?)	There need not be a difference between requests for PAD and requests for other end-of-life medical treatments. We think it is contrary to a patient's right to privacy to require a witness.
ROLE OF PHYSICIANS	
What is the appropriate role of physicians in physician-assisted dying? For example: • **Should a physician's role be to actively administer the medication that causes death if requested to do so by a patient who meets the eligibility criteria?** • **If an eligible patient prefers, and has the ability, should a physician's role be to prescribe the lethal medication which the patient would then administer themselves?** • **Should physicians always remain with the patient until the time of death?**	The SCC ruling is silent on whether a physician must administer or a patient may administer medication to themselves. For reasons of patient safety we agree with DWD's submission that administration by IV or injection should be done by a doctor or nurse under the supervision of a doctor. If prescribed orally, there should be no requirement for a physician to be present even though it may be encouraged. A patient must be free to take their life-ending medication in a place of their choice and in the company of people that they choose.

ROLE OF OTHER HEALTH CARE PROVIDERS	
What is the appropriate role of non-physician regulated health care professionals in the provision of PAD?	The SCC recognized the right to a physician-assisted death. A physician must be involved. If medication is administered intravenously, we have no objection to an appropriately-regulated health-care professional under the direct and active supervision of a physician administering the medication, as is the case in other forms of medical care. It is not clear that the SCC ruling supports the administration of medication by non-physicians. This could require an amendment to the Criminal Code of Canada. Pharmacists will, of course, have to ensure availability of the required medication, subject to the conscientious objection answer provided below.
Should non-physician regulated health care professionals (e.g., Registered Nurse, Nurse Practitioner) acting under directives from a physician be allowed to fulfil a request for PAD?	We have answered this question above.

What is the appropriate role of non-regulated health workers in the provision of PAD?	We do not believe there is a role for non-regulated workers in the provision of PAD.
CONSCIENTIOUS REFUSALS BY HEALTHCARE PROVIDERS	
Should physicians have the right to refuse to provide PAD for reasons of conscience? If yes: • **What continuing obligations, if any, do they have to the patient?** • **Does the right to refuse include the right to refuse to provide an effective referral for PAD?** *See Appendix 4 for additional information.*	All physicians are required to provide information about physician-assisted dying according to the established norms of informed consent law. Physicians are not required to provide physician-assisted death. The patient’s right to access physician-assisted dying must be reconciled with the right of their physician to conscientiously object to providing that treatment. In order to reconcile these two competing rights, it should be recognized that the conscientious objector has a duty to immediately notify the patient of their objection, and to immediately inform a third party (for example, a hospital, local health authority, or the provincial or territorial regulatory college) of their objection. The third party should be placed under a responsibility to contact the patient as soon as possible to provide a referral to a willing physician. A physician must obtain the consent of the patient to disclose the request to the third party, and consent for that agency to contact the patient. A physician must not abandon the patient, or discuss in detail their personal beliefs or pressure patients to disclose or justify their own beliefs.

Should non-physician regulated health care professionals (e.g., Registered Nurse, Nurse Practitioner, Pharmacist, etc.) have the right to refuse to participate in the provision of PAD for reasons of conscience? • **If so, under what circumstances?**	Pharmacists are required to provide information about physician-assisted dying according to the established norms of informed consent law. Pharmacists are not required to fill prescriptions for life-ending medication. It should be recognized that the conscientious objector has a duty to inform their manager of their objection so that an alternative pharmacist can dispense the medication. If there is no manager or alternative pharmacist within the pharmacy to willingly dispense the medication, then pharmacist must immediately inform the patient of their objection, and immediately inform a third party (for example, a hospital, local health authority, or the provincial or territorial regulatory college) of their objection. The third party should be placed under a responsibility to contact the patient as expeditiously as is practicable to provide a referral to a willing pharmacist. A pharmacist must obtain the consent obtain the consent of the patient to disclose the request to the third party, and consent for that agency to contact the patient. A pharmacist must not discuss in detail their personal beliefs or pressure patients to disclose or justify their own beliefs.
ROLE OF INSTITUTIONS	
What is the appropriate role of health care institutions (e.g., hospitals, hospices, long-term care facilities, etc.) in making PAD services available to patients?	While it remains for provincial health ministries to make decisions as to resource allocation among institutions, in general, all institutions providing public healthcare services should be required to provide or facilitate the provision of PAD at their facility. In its resource-allocation choices, governments must ensure that a complete range of medically-required hospital services are available to every resident, and specifically, they must ensure that PAD, which is a constitutional right, is accessible.

On what issues in particular does your organization feel that health institutions need specific guidance – through legislation, regulation, or guidelines – for the implementation of PAD services?	It must be made clear that all institutions that deliver services under provincial healthcare plans must provide or facilitate the provision of PAD. They may also require guidance on the kind of information that needs to be provided as to meet the requirements of informed consent. Guidance must be provided as to the process for physicians who conscientiously object, and patients must be aware of how that process works. An institution must not discriminate against physicians who provide PAD at other institutions or in any way impede their ability to provide the treatment elsewhere. Purely private institutions, such as hospices, must disclose to patients up front whether or not they allow PAD.
Should health care institutions be required to provide PAD at their facility? If yes, please explain why. If no, under what circumstances and what responsibility should the institution have to ensure patients have access to PAD?	While individual physicians and pharmacists must be able to refuse to provide PAD, denominational hospitals that are integral parts of the healthcare system should be required to permit willing physicians and willing patients to access PAD within their institutions. It is a clear principle of constitutional law, established in the Eldridge SCC decision, that the Charter applies to public healthcare delivered in hospitals. Hospitals "in providing medically necessary services, hospitals carry out a specific governmental objective." While private actors may deliver the service, the government is responsible for it and cannot escape its Charter duty. Conscientious objection is a carefully qualified claim, and it is not practicable for institutions to make such claims in respect of PAD as significant hardship could result to patients.

What should be the responsibility of the health care institution to the patient when a physician within the facility refuses to provide PAD for reasons of conscience and/or provide an effective referral for PAD in a case where the requesting patient meets the eligibility criteria?	As discussed, a physician should have a duty to notify a third party of their objection. If this takes place in a healthcare institution, the institution should be notified by the physician and must ensure that the patient is contacted in relation to PAD expeditiously, and that the patient is not abandoned in their request. The institution must ensure the patient's effective referral to a willing physician.
ACCESS	
What barriers to access do you foresee that will need to be addressed in implementing PAD? In what ways do you think these barriers could or should be reduced? **Where access to PAD is limited by these barriers, what steps should be taken to facilitate access for patients seeking the service?**	We have discussed the barriers posed by conscientious objection. We are concerned about geographic barriers within a province. Governments must ensure that people have access to PAD wherever they live. This access should be provided within their home community, wherever possible. By "possible", we mean that governments must take considerable lengths to ensure that this constitutionally-guaranteed right is accessible. End-of-life care is often most effective and humane at home or close to home, where patients can be near loved ones and in familiar settings. Access to PAD within an individual's home, home community, or home region should be the standard.

What unique implementation issues, if any, do you foresee for PAD in rural or remote settings? How should they be addressed?	As above. Provinces should consider the remote medicine tools that may assist in assessments related to PAD. In communities in which there are no willing physicians, the province should pay for a physician to travel to administer PAD. As an aside, though cost is not the governing consideration in ensuring the availability of a constitutionally-guaranteed right, we observe that taking a doctor to the patient might in many cases be cheaper to the government and would almost certainly be less burdensome to the patient and family than moving a patient to a distant urban centre.
How could and should provincial/territorial governments ensure equitable access to PAD?	Provinces and territories must ensure access to life-ending medication and availability of life-ending medication [scheduling and stock]. Governments must provide that physician-assisted dying is available to insured persons within the meaning of provincial and territorial health insurance legislation, or equivalent federal programs, such as those for members of the Canadian Forces, federal inmates, and beneficiaries of the Interim Federal Health Program. There must be no penalty for physicians who provide PAD to those who are not insured persons.

If it is determined that a patient is ineligible for PAD, should the patient have a right to appeal that decision? If so, what process should be used and to whom should the appeal be directed?	Yes, there must be a right of a timely and fair appeal. In our view it would compromise fairness to have individuals on any appeal panel that oppose PAD. The purpose of such an appeal should be to determine whether the patient is eligible (if the patient was determined to be ineligible) or competent (if the patient was determined not to be competent), and not whether PAD is an option to be preferred. Eligible, competent adults must have access to PAD, and denying PAD to such patients is unconstitutional.
SETTINGS	
In what health care settings should PAD be provided? *See Appendix 5 for additional information.*	Patients should be able to access PAD wherever they live, including their home, long-term care home, retirement home or hospice, and of course in hospitals and healthcare institutions. If a private institution objects, that objection must be communicated up front to prospective residents/patients. For individuals currently living in private institutions, the institutions should be required to notify all existing residents/patients.

If PAD were provided at home, what implementation issues would this raise? How should they be addressed?	Consideration should be given to the availability of emergency medical care in the event that something goes wrong in the administration of the medicine.
Are there other implementation issues related to the settings in which PAD might be provided that need to be addressed?	We agree with DWD that patients administering at home must be able to have custody of the medication. Patients should be aware of precautions in relation to the medication's use, storage, and security from others, as with any other medication.

CASE REVIEW AND OVERSIGHT	
What reporting (including documentation) should be required of the physician following the provision of PAD? How should this reporting be done? Who should receive the reports? *See Appendix 6 for additional information.*	To ensure appropriate oversight, provincial/territorial legislation should establish a duty for physicians to report PAD to the provincial/ medical licensing authorities or other designated agency to assess quality of care particularly with respect to applicable clinical standards. Such reporting must respect patient privacy. We agree with DWD that doctors or institutions should complete the death certificate, insurance forms if necessary, as well as the report to the designated agency. We share the concern that onerous reporting, and lack of compensation for reporting, may present barriers to access by discouraging physicians from providing PAD, and therefore, such reporting should be relatively simple and compensated.
Should there be a review of each case of PAD? If yes: • **Should it be undertaken before or after the assistance is provided?** • **Who should undertake the review?** • **What standards (e.g., clinical, professional, legal) should be used in the review?** • **To whom should the reviewer(s) report any findings of non-compliance with the standards?** **If there should be no review, why not?**	No. PAD should be treated in the same way as other end-of-life decision-making. There is no evidence to suggest that individual case review is necessary and it would impose a completely unnecessary barrier to access, either by introducing a hurdle pre-PAD, or by creating undue extra work for physicians and the medical system post-PAD.

Should an oversight body be established? If yes: • **Should it be national or provincial/territorial?** • **Should it be administered by government or by regulatory bodies?** • **What role and responsibilities should it have?** • **What should its composition be, in terms of the number of members and their backgrounds?** • **What should be its obligations for public reporting and quality improvement?** • **What other considerations are relevant to an oversight system, process, or body?**	We support the proposition that accurate data about PAD should ideally be collected on a national basis. Legislation should establish a duty for Medical Licensing Authorities or the designated agencies referred to above to report PAD to some national body established either by the federal government or jointly established provincial health ministries for the purpose of data collection. If a national body is not feasible, some agency should provide this role at a provincial level. An oversight body should produce public data and reports. It should be composed principally of physicians. The right to PAD having been established, the body should not consider issues of whether PAD should be available. It should report on accessibility and other measures related to PAD.
ADDITIONAL SUPPORTS	
What, if any, educational materials should be developed for and provided to physicians and other health care providers? Who should be responsible for developing these materials (e.g., provincial/territorial governments, professional bodies, provincial Colleges of Physicians and Surgeons)?	This is not our area of expertise. The materials need to ensure that physicians are able to provide information to patients that is sufficient to allow patients to make informed choices and exercise informed consent about PAD.

Should an independent organization be established to support physician practice (e.g., information, training) and/or facilitate patient access to PAD services? • **If so, who should establish it? What should it be tasked to do?** • **If not, what organization(s) should assume this responsibility?**	This is not our area of expertise. However, governments need to ensure that physicians are able to provide information to patients that is sufficient to allow patients to make informed choices and exercise informed consent about PAD. Governments need to ensure that access to PAD is facilitated for all qualifying patients who seek it.
What other resources should be developed to support physicians and other health care providers in relation to PAD?	This is not our area of expertise. Whatever resources and supports are necessary for physicians to be able to provide information to patients that is sufficient to allow patients to make informed choices and exercise informed consent about PAD, and for physicians to offer PAD to eligible patients, should be provided. Whatever resources that might be beneficial to institutions in facilitating PAD should also be provided.

What resources should be developed to support patients and their families/caregivers in relation to PAD?	Patients require detailed information to make informed choices and to provide informed consent. Health ministries should produce materials explaining choices to families and caregivers, emphasizing that the choice lies with the patient, regardless of how family members feel about that choice.
ADDITIONAL INPUT	
Is there anything else, not covered above, that your organization considers relevant to the implementation of PAD? Please use this space or attach additional comments to your e-mail response.	We reiterate: Physician assisted dying (PAD) is a private matter between a physician and patient, like all other treatment decisions at the end of life or otherwise. Physician-assisted dying can and should be treated like other medical decisions, and be governed by the established norms of informed consent law, which has shown itself to be perfectly adequate as a framework for life-and-death medical decisions. The BCCLA favours consistent standards across Canada for physician-assisted dying, so that individuals who are entitled will have timely equal access to PAD regardless of the province, territory, or region in which they live. Life insurance companies should not be able to refuse to pay life insurance benefits for terminal illness because death occurred by way of PAD.