CENTRE DE RECHERCHE
INSTITUT UNIVERSITAIRE
DE CARDIOLOGIE
ET DE PNEUMOLOGIE
DE QUÉBEC
UNIVERSITÉ LAVAL

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September 30, 2025

Give A Breath Research Award Review Committee
Lung Cancer Canada

Subject: Application for the 2025 Give A Breath Research Award

Dear Esteemed Members of the Review Committee,

I am pleased to submit this application for the 2025 Give A Breath Research Award. Our proposed project, *Characterizing Treatment Patterns and Decision-Making in Lung Cancer Patients Pursuing MAiD*, directly aligns with the Award's objective of supporting research focused on patients with advanced lung cancer beyond first-line treatment.

Lung cancer patients represent the largest group of individuals requesting medical assistance in dying (MAiD) in Canada, yet little is known about their treatment trajectories, access to therapies, or the decision-making processes leading to MAiD. Existing studies are limited by retrospective designs and incomplete documentation of symptom burden and palliative care integration. This project will be the first prospective Canadian study to examine these issues within a specialized lung oncology program at a university-affiliated hospital in Québec City.

Our multidisciplinary team brings together leading Canadian and international researchers in oncology, palliative care, and health services research, as well as experienced clinicians caring for this population. This combination of internationally recognized expertise, national representation, and clinical engagement is a key strength of the project.

Support from the Give A Breath Research Award will enable us to generate actionable evidence to improve clinical practice, inform health policy, and lay the foundation for a future multi-provincial cohort. This project will also allow us to develop this new avenue of research within our team and to establish a sustained research focus on decision-making and care trajectories for patients with advanced lung cancer. We are committed to producing findings that will have a tangible impact on the quality of care and decision-making for patients and families at the end of life.

We appreciate your time and careful consideration of our application.
With highest consideration,

Diane Tapp, RN, PhD
Full Professor, Université Laval
Researcher, Quebec Heart and Lung Institute Research Center (IUCPQ)
Co-Director, Quebec Network for Palliative and End-of-Life Care Research (RQSPAL)
Email: diane.tapp@fsi.ulaval.ca

Characterizing Treatment Patterns and Decision-Making in Lung Cancer Patients Pursuing MAiD

Give a Breath Research Award – Lung Cancer Canada
September 2025

Principal Investigator
Diane Tapp, PhD – Professor, Faculty of Nursing, Université Laval; Researcher, Quebec Heart and Lung Institute Research Center (IUCPQ); Co-Director, Quebec Network for Palliative and End-of-Life Care Research (RQSPAL), Quebec, Canada

Co-Investigators
Catherine Labbé, MD, Pulmonary Oncologist and Head of the Department of Pulmonology, clinical researcher– Quebec Heart and Lung Institute Research Center, Quebec, Canada
Lynn Gauthier, PhD, Researcher – CHU de Québec – Université Laval Research Center, Quebec, Canada
James Downar, MD Clinical researcher– Faculty of Medecine, University of Ottawa, Ottawa, Canada
Aline Hajj, PhD Researcher– Faculty of Pharmacy, Université Laval, Quebec, Canada
Breffni Hannon, MD – Princess Margaret Cancer Centre, Toronto, Canada

Collaborators
Mireille Villeneuve, Nurse Practitioner, Palliative Care– Quebec Heart and Lung Institute, Quebec, Canada
Marie-Joëlle Pelletier, Nurse Practitioner, Pneumology– Quebec Heart and Lung Institute, Quebec
Patient partners (to be recruited)

Summary of the proposed research

Introduction / Background

Lung cancer is the leading cause of cancer-related mortality in Canada, accounting for nearly one in four cancer deaths each year. Although therapeutic advances have been achieved in recent years, particularly with targeted therapies and immunotherapies, many patients continue to present with advanced disease and limited survival. For this population, the trajectory of care is often marked by complex decision-making, substantial symptom burden, and repeated encounters with the health care system. Disparities in access to systemic therapies also exist across socioeconomic, cultural, and geographic lines.

Recent data from Québec confirm the importance of lung cancer in the context of medical assistance in dying (MAiD). Between 2018 and 2023, lung cancer accounted for 28.7% of cancer-related MAiD cases, a proportion much higher than any other tumor type[1*]. At the national level, the Government of Canada's MAiD annual report has also consistently shown that lung cancer is among the cancers most frequently represented among patients pursuing MAiD[2].

Several Canadian studies have deepened our understanding of this phenomenon. Moore et al. (2022) reported that fewer than 50% of lung cancer patients receiving MAiD had systemic therapy[3]. In a multicenter cohort, Thabet et al. (2023) found 62% received at least one line of therapy suggesting differential access to treatment[4]. Patients were typically older (median age 72) and functionally impaired, with up to 90% ECOG 3–4. Symptom burden was high, with dyspnea, fatigue, and pain being the most prominent and difficult to manage. Liu et al. (2022) and Thabet et al. (2023) noted that while many patients were assessed by oncology at some point, access to oncologists and palliative care teams was often limited in the final month of life[4,5] with up to 62% of patients having no oncology follow-up in the 30 days before MAiD, and palliative care was introduced late. To date, no prospective study in Canada has documented the care trajectories and decision-making processes of patients with lung cancer pursuing MAiD.

Systematic and scoping reviews show that early integration of palliative care in lung cancer improves quality of life, reduces symptom intensity, and lowers emergency department visits and hospitalizations[6–8]. In clinical practice, referrals to palliative care often occur very late, sometimes only in the last weeks of life, highlighting a critical gap in care delivery.

Taken together, these findings highlight the importance of studying, in a prospective manner, the treatment trajectories, symptom burden, and decision-making processes of lung cancer patients who pursue MAiD. Such research is needed to identify gaps in access to therapies and supportive care, and to better understand how patients and families navigate the final stages of life in the context of lung cancer.

Research Question

How do treatment trajectories, symptom burden, and decision-making processes influence the pursuit of medical assistance in dying among patients with lung cancer?

Objectives

The general objective of this study is to characterize the care trajectories, the symptom experience, and the decision-making processes of patients with advanced lung cancer who pursue MAiD.

The specific objectives are:

1. To characterize treatment access and patterns in patients with lung cancer requesting or receiving MAiD, with attention to systemic therapy use (chemotherapy, immunotherapy, targeted therapy) and differences between Non-Small Cell (NSCLC) and Small Cell (SCLC) lung cancer subtypes.
2. To examine timing and nature of palliative care integration and its relationship with symptom burden, health care utilization, and care trajectories.
3. To document the symptom burden, functional status (e.g., dyspnea, fatigue, pain, ECOG performance status) and associated comorbidities.
4. To explore decision-making factors, including patient- and family-reported reasons for requesting MAiD (disease/symptom burden, fear of suffering, desire for autonomy), and the perceived role of oncology, palliative care, and psychosocial support in these decisions.

Methods

This investigation will be conducted as a **collaborative prospective, mixed-methods observational study** at a specialized lung oncology program in a university-affiliated hospital in Québec City. The study will span **12 months of recruitment**, during which both quantitative and qualitative data will be collected in order to provide a comprehensive portrait of the experiences of patients with lung cancer who pursue MAiD. The research team will include researchers, clinicians specializing in pulmonary oncology and palliative care, and patient and family partners.

The **study population** will include adults aged 18 years or older with a confirmed diagnosis of NSCLC or SCLC who have formally submitted a MAiD request, are able to provide informed consent. Exclusion criteria include significant cognitive impairment precluding informed consent, severe medical instability preventing participation, and inability to communicate in French or English. **Recruitment** will be carried out in collaboration with the hospital's oncology and palliative care services (Figure 1). Treating physicians will inform eligible patients about the study and, with their permission, refer interested individuals to a research nurse. The nurse will provide a detailed explanation of the study, answer any questions, and obtain informed consent. We aim to recruit a total of 20–25 participants over the 12-month study period, which is a realistic target given the annual number of eligible patients at this institution. Recruitment for qualitative interviews will continue until thematic saturation is reached. This sample size will be sufficient to support descriptive quantitative analyses and to generate a rich qualitative dataset for thematic exploration.

Data collection will combine several complementary sources. Clinical and treatment data will be extracted from medical records and will include demographics, socioeconomic characteristics, smoking history, tumor subtype and stage, and details of prior cancer-directed therapies (systemic treatments, radiotherapy, and surgery). Information on the number and timing of MAiD requests, and whether provision occurred, will be documented. Functional status will be measured using the ECOG performance scale, and symptom burden will be assessed with the Edmonton Symptom Assessment System revised (ESAS-r), focusing on dyspnea, fatigue, and pain. Social determinants such as socioeconomic status, family support, health literacy, and knowledge of therapies and palliative care will also be examined.

The study will document the timing, type, and extent of palliative care integration (inpatient/outpatient, multidisciplinary involvement). Decision-making processes will be explored through structured patient interviews capturing motivations such as disease burden, autonomy, and fear of suffering. Health system utilization will be assessed via oncology and palliative care consultations, hospitalizations, and emergency visits in the 90 days preceding death, and the location of death.

Quantitative data will be analyzed using descriptive statistics. Subgroup analyses will compare patients by lung cancer subtype, receipt of systemic therapy, and timing of palliative care integration. Exploratory analyses will examine associations between treatment patterns, symptom burden, and MAiD timing. **Qualitative data will be analyzed inductively** using MAXQDA (v24.11.0) and interpreted in light of shared decision-making frameworks[9], reflecting dimensions already described in Canadian cohorts[3,5]. Two researchers will code independently, with consensus procedures and a reflexive journal to ensure rigor. Integration of quantitative and qualitative data will rely on triangulation using joint displays and a convergence coding matrix. This approach will allow systematic comparison across datasets and support the generation of robust meta-inferences. Ethical approval will be obtained from the institutional ethics committee prior to study initiation. Informed consent will be mandatory for all participants. Procedures will be conducted by research nurses trained in palliative care, with psychosocial support available as needed. The study is designed to balance research objectives with participant vulnerability, ensuring dignity, comfort, and safety. Previous Canadian studies[3–5] confirm feasibility and ethical acceptability of similar approaches. Data will be anonymized and securely stored in institutional servers, accessible only to the research team. The project includes a comprehensive knowledge translation plan tailored to clinical, academic, and policy audiences (see Table 2). A detailed project timeline outlining key milestones and deliverables is provided in Figure 2.

Impact Statement

This study will be the **first prospective Canadian investigation of treatment patterns and decision-making among patients with advanced lung cancer pursuing MAiD**. By documenting access to therapies, timing of palliative care, symptom burden, and psychosocial factors influencing decisions, the project will identify gaps in care and highlight opportunities for improvement. In particular, it will shed light on inequities in access to systemic therapies, evaluate palliative care integration, and examine how symptoms and psychosocial distress shape MAiD requests.

The project **brings together investigators from different Canadian provinces and internationally recognized experts**. This diversity of perspectives will strengthen the scientific quality of the study and support the planning and feasibility of a subsequent pan-Canadian cohort phase. The involvement of **clinical team members as collaborators and co-investigators will ensure strong alignment with local clinical realities and maximize the project's relevance and impact, both locally and nationally**.

For patients, the findings will help **promote equitable access to therapies, timely palliative care, and better symptom management, ultimately improving quality of life in advanced illness**. For clinicians, the study will provide new insights into patient and family experiences, supporting earlier referrals, more effective communication, and shared decision-making.

At a broader level, the project **will highlight systemic gaps in access to innovative treatments and supportive care, pointing to opportunities to reduce disparities**. While it is not expected to directly affect lung cancer incidence or mortality, the study will **improve end-of-life outcomes and patient-centered care, foster better integration between oncology and palliative care, and support equitable, informed, and compassionate MAiD decision-making.**

Non-Scientific Summary

Lung cancer is the leading cause of cancer death in Canada, responsible for nearly one in four cancer-related deaths. Despite recent advances such as immunotherapy and targeted treatments, many patients are diagnosed at an advanced stage and face significant symptoms such as shortness of breath, fatigue, and pain. These symptoms not only affect quality of life but also influence important decisions at the end of life, including whether to request medical assistance in dying (MAiD).

Data from Québec show that lung cancer is the cancer most often associated with MAiD requests, representing nearly 30% of all cases. Yet, very little is known about the care that these patients receive before making this decision. Studies suggest that fewer than half of patients with lung cancer who eventually receive MAiD are treated with systemic therapy, and that access to early palliative care remains inconsistent. Furthermore, much of the research to date has been retrospective, meaning it looked back at charts after patients had already died, rather than collecting information prospectively from patients themselves.

This project will address these gaps by following lung cancer patients who request MAiD at a specialized oncology center in Québec City. We will document what treatments they received, whether they had access to new therapies, when they were referred to palliative care, and what symptoms they experienced. We will also meet with patients, when possible, to better understand the reasons behind their request for MAiD and how health professionals influenced their decisions.

By combining information from the patient's medical records with their own experiences, the project will provide unique insights into the care experiences of lung cancer patients at the end of life. The findings will help identify gaps in treatment access, highlight the importance of timely palliative care, and shed light on the factors that matter most to patients when making end-of-life decisions.

Ultimately, this research will support improvements in how health care teams accompany patients with advanced lung cancer. It will ensure that decisions about MAiD are made in the context of the best possible care, with equitable access to treatments, effective symptom management, and respect for patient values and autonomy.

Budget

1. Human Resources

Research Professional, Category 3 (n=1)
The research professional will be a palliative care–trained research nurse holding a Master's or PhD degree, who will be responsible for the execution of the project's scientific activities.

Main responsibilities:

- **Project coordination:** coordinate with the medical team, schedule and conduct meetings with participants, and carry out interviews.
- **Data analysis:** conduct both qualitative and quantitative analyses.
- **Knowledge production:** draft a scientific manuscript for publication.
- **Reporting:** prepare the final research report for Lung Cancer Canada.

Research Professional, Category 3, Level 5
Salary: $41.24/h × 7h × 52 weeks = $15,011.36
Benefits (19.27%) = 2,892.69
Total for 1 year = $17,904.05

Research Assistant (n=1)
The involvement of a research assistant is essential to ensure high-quality data collection. The assistant will be an undergraduate student in health sciences.

Main responsibilities:

- **Data management:** extract relevant data from patient medical records.
- **Transcription verification:** review and verify verbatim transcripts of individual interviews.
- **Research support:** assist the research coordinator with various tasks, including interviews and meetings with participants.

Research Assistant
Salary: $20.66 × 160h (over 8 months) = $3,305.60
Benefits (12.55%) = $414,85
Total = $3,720.45

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2. Monetary compensation for participation at the interview

Participants will be compensated for their time and, if applicable, for parking. If the team needs to travel to the participants' homes, additional costs will be covered.

25 participants x 25$ = 625$
Total = 625

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3. Patient partners compensation

Two patient partners will be involved to support the research team at key stages of the project, including before ethics submission, after recruitment, and at the end of the project.
$50/meeting x 3 meetings x 2 people = $300
Total = $300

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4. Open Access Publication in *Lung Cancer Journal*

Publication fees: USD 3,320 (excluding taxes), approximately CAN $5,300*.
*A portion of these costs (approximately $3,000) will be covered through additional funding secured from the Quebec Network for Palliative and End-of-Life Care Research (RQSPAL).
Total: $2,300

Total Budget: $24,849.50

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September 1st, 2025

Review Committee
Give A Breath Research Award - Lung Cancer Canada
133 Richmond St. W., Suite 208, Toronto, ON, M5H 2L3

Re: Institutional Letter of Support – Dr. Diane Tapp

Dear Members of the Review Committee,

On behalf of the Research Center of the Institut universitaire de cardiologie et de pneumologie de Québec – Université Laval (CRIUCPQ-ULaval), I am pleased to provide our strong institutional support for the application submitted by Dr. Diane Tapp to the 2025 Give A Breath Research Award. Her project, *Characterizing Treatment Patterns and Decision-Making in Lung Cancer Patients Pursuing MAiD*, addresses a pressing and underexplored issue in the care of individuals with advanced lung cancer.

The CRIUCPQ-ULaval is internationally recognized as a leading center for clinical care and research in pulmonary diseases, including lung cancer. As a university-affiliated institute, our mission is to integrate clinical excellence with innovative research, ensuring that patients with pulmonary conditions have access to the most advanced therapies and to cutting-edge studies that shape the future of care. Our institution has a long-standing reputation for excellence in thoracic oncology, multidisciplinary cancer care, and the development of innovative approaches to improve outcomes for patients with advanced disease.

Dr. Tapp's expertise as a senior researcher in palliative and end-of-life care is a critical complement to our institutional strengths in pulmonary oncology. She brings a nationally and internationally recognized track record in advancing knowledge on symptom management, care trajectories, and medical assistance in dying (MAiD). Her project will leverage the CRIUCPQ-ULaval's unique access to lung cancer patients and its strong clinical-research integration, while adding her leadership in palliative care research to generate evidence that bridges oncology and supportive care.

We are confident that this project will not only advance scientific knowledge but also have a direct and meaningful impact on patient care. By combining the CRIUCPQ-ULaval's expertise in pulmonary oncology with Dr. Tapp's leadership in palliative care research, the study will provide new insights into treatment access, palliative care integration, and decision-making processes for patients and families navigating the challenges of advanced lung cancer and MAiD.

The CRIUCPQ-ULaval fully endorses this application, confirms the feasibility of conducting the study within our institution, and commits to providing the infrastructure, ethical oversight, and administrative support required for its success.

Sincerely,

Mathieu Laplante, PhD
Director, Research Center
Institut universitaire de cardiologie et de pneumologie de Québec – Université Laval

Appendix

Table 1. References

1. Commission sur les soins de fin de vie. *Rapport Sur La Situation Des Soins de Fin de Vie Au Québec 2018-2023*. (2023).

2. Government of Canada. *Rapport Annuel Sur l'aide Médicale à Mourir 2023*. (2023).

3. Moore, S., *and al*.. Medical assistance in dying (MAiD) in patients with cancer. *J. Clin. Oncol.* (2022)

4. Thabet, C., *et al.* Medical Assistance in Dying in Patients With Cancer. *JCO Oncol. Pract.* 19, 819–827 (2023).

5. Liu, T. *et al.* Medical Assistance in Dying in Oncology Patients: A Canadian Academic Hospital's Experience. *Curr. Oncol.* 29, 9407–9415 (2022).

6. Haun, M. W. *et al.* Early palliative care for adults with advanced cancer. *Cochrane Database Syst. Rev.* (2017)

7. Hui, D., Hannon, B. *et al.* Improving Patient and Caregiver Outcomes in Oncology: Team-Based, Timely, and Targeted Palliative Care. *CA. Cancer J. Clin.* 68, 356–376 (2018).

8. Kang, E. *et al.* Early Integrated Palliative Care in Patients With Advanced Cancer: A Randomized Clinical Trial. *JAMA Netw. Open* 7, e2426304 (2024).

9. Elwyn, G. *et al.* Shared Decision Making: A Model for Clinical Practice. *J. Gen. Intern. Med.* 27, 1361–1367 (2012).

Table 2. Project Results Dissemination Plan

Communication objective	Dissemination Venue	Activity description
Disseminate scientific results	Congrès québécois en santé respiratoire (November, 2026) and possibly, Canadien Lung cancer Conference (February, 2027)	**Oral communication of key findings** to the national scientific community, fostering knowledge exchange and discussion on implications for clinical practice and policy.
Disseminate scientific results	Open Access Scientific Journal	**Publication of a peer-reviewed article** (*Lung Cancer journal* (IF 4.4)) to reach the international scientific community, ensuring visibility, accessibility, and contribution to global evidence on MAiD and lung cancer.
Raise public awareness	Online – Principal Investigator's social media	**Dissemination of a short science communication video** to popularize the study results for the general public, enhancing health literacy and promoting informed societal dialogue.

Figure 1. Methological framework

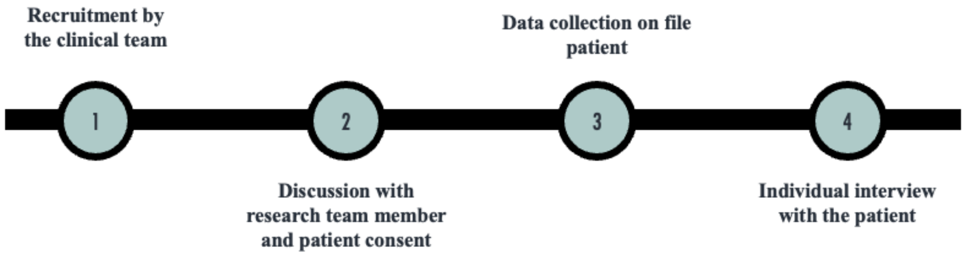

Figure 2. Project Timeline

	2026											
	January	**February**	**March**	**April**	**May**	**June**	**July**	**August**	**September**	**October**	**November**	**December**
Obtain ethics approval	▨											
Recruit participants and collect data		▨	▨	▨	▨	▨	▨	▨	▨			
Conduct qualitative analysis		▨	▨	▨	▨	▨	▨	▨	▨			
Conduct qualitative analysis									▨	▨		
Present at the *Congrès québécois en santé respiratoire*											▨	
Create a science communication video											▨	▨
Write a scientific article										▨	▨	▨