

A/Prof. Vishal Navani, MA (Oxon) MBBS (Lon) MRCP (UK) FRACP

Staff Medical Oncologist, Section of Medical Oncology
Staff Medical Oncologist, Arthur Child Comprehensive Cancer Centre, Calgary
A/Prof. Clinical, Cumming School of Medicine, University of Calgary
3395 Hospital Drive N.W. Calgary, AB, Canada T2N 5G2
1331 – 29th Street NW, Calgary, AB T2N 4N2
T: 587-231-6051 F: 587-231-5077

February 7, 2025

Lung Cancer Canada: **Letter of Intent for 2025 Lung Ambition Award**

Dear Lung Cancer Canada's Research Committee,

On behalf of the Glans-Look Lung Cancer Research group, a national leader in gathering real-world evidence on lung cancer, please accept this Letter of Intent to express our strong interest in applying for funding from the 2025 Lung Ambition Awards to support our proposed project, **"EXPAND the Voices of PROPEL"**.

A lung cancer diagnosis changes an individual into a 'patient' and their family or social circle into 'caregivers,' each with unique experiences and impacts on their well-being and quality of life. While the challenges of a lung cancer diagnosis are understood, they have not been fully explored from the perspectives of those directly affected - patients and caregivers. This highlights an unmet need and an opportunity to better integrate PROMs related to well-being and quality of life into personalized medicine.

Supported through funding from the Terry Fox Institute and the Marathon of Hope Cancer Centre's 'Patient Voices in Research' grant, the **PROPEL project (Patient Reported Outcomes in People Experiencing Lung Cancer)** was launched in early 2025 in four Albertan cities (Calgary, Edmonton, Red Deer, and Grande Prairie) to explore the feasibility and best practices of collecting PROMs outside the healthcare system. Using self-referral, electronic consent and PROMs distribution, **PROPEL** offers an accessible way to gather the lived experiences of lung cancer patients and caregivers, using validated PROMs approved by a team of patient and caregiver research partners.

Alberta is a diverse province, and the Lung Ambition Award funding offers a chance to build on the vision of the **PROPEL** project by **increasing Empowerment, understanding the lived experience, Promoting Awareness, Navigating the lung cancer journey, and Developing resilience to EXPAND the Voices of PROPEL**. This support would allow recruitment from all 17 provincial cancer care centers, improving inclusivity for rural, remote, indigenous and diverse communities. It would also broaden the analyses to identify key PROMs themes, uncover resource gaps, and highlight groups with unmet needs in the lung cancer community.

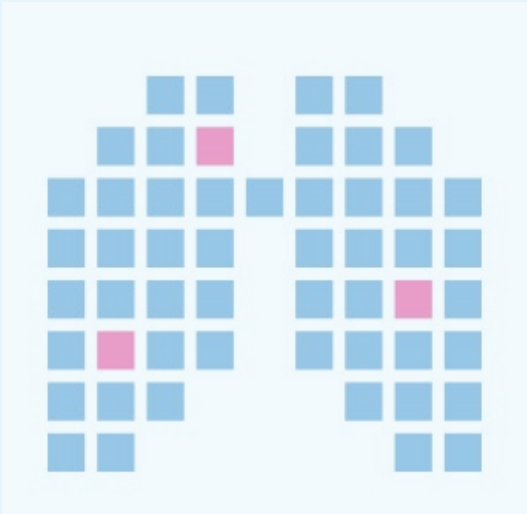
Thank you for considering our application and the opportunity to undertake projects to better understand the lived experience of lung cancer and move towards a future which optimizes the well-being for patients, caregivers and the Alberta community alike.

Sincerely,



Dr. Vishal Navani

EXPAND
the Voices of



Glans-Look Lung Cancer Research

PROPEL Study

Contents

Proposal Summary.....	1
Background & Knowledge to Date:.....	1
Methods:.....	1
Anticipated Results & Conclusions:	2
Challenges:.....	2
Knowledge Mobilization:	2
Tables and Figures:	3
Figure 1:	3
Figure 2:	3
Figure 3:	4
Figure 4:	4
Impact Statement	5
Public Summary.....	6
Budget.....	7
Investigator/CO-I CV	7
Statement of Support from Institution	7

Proposal Summary

EXPAND the Voices of PROPEL

Background & Knowledge to Date:

Lung cancer is the leading cause of cancer-related death in Canada but receives inadequate research funding. While often viewed as a preventable "smoker's disease," up to 20% of cases occur in never-smokers, particularly affecting younger women. Nearly half of lung cancer diagnoses are made at an advanced, incurable stage, intensifying its societal impact.

The physical, psychosocial, and functional effects of cancer and caregiving vary greatly, influenced by both cancer-related (disease extent, treatment side effects, healthcare access) and non-cancer factors (demographics, socioeconomic status, geography). These factors can create inequities and underserved populations within cancer care.

As cancer care shifts toward patient-centered, personalized medicine, understanding the lived experience of both patients and those who identify in a caregiving role (physical, practical, social or emotional) is crucial. Incorporating the "right personal context" alongside the "right drug at the right time" requires inclusion of patient and caregiver voice to understand the physical and psychosocial impacts of cancer. The lived experience can be captured using validated patient-reported outcome measures (PROMs).

The **PROPEL** Study (**Patient Reported Outcomes in People Experiencing Lung Cancer**), described [here](#), was designed by the Glans-Look Lung Cancer Research group at the University of Calgary, aims to collect comprehensive PROMs measures on wellbeing and health-related quality of life from Albertans affected directly (patients) or indirectly (caregivers) by lung cancer. **PROPEL** was initially designed to capture the impacts of an advanced lung cancer diagnosis and treatment on patients and caregivers in four major Alberta centers (Calgary, Edmonton, Red Deer, and Grande Prairie), with support from local oncologists and patient and caregiver ambassadors. Inclusivity - encompassing demographic, socioeconomic, geographic and cultural diversity, and equity-seeking and marginalized populations - is crucial. There is a need to **EXPAND** (Empowerment, Lived eXperience, Promoting Awareness, Navigating the lung cancer journey, and Developing resilience) the voices of **PROPEL** to ensure comprehensive representation, identification of specific groups with unmet needs, and a means to address these barriers to well-being. This current proposal seeks support to **EXPAND the Voices of PROPEL** to target enrollment from people with advanced lung cancer and their caregivers in other regions of Alberta, specifically those served within [regional and community cancer centers](#) to increase participation, promote inclusivity and capture diversity.

Methods:

Funding for a **PROPEL** project coordinator who will promote study awareness, liaise with local/community oncologists and patient advocate/ambassadors, and undertake local outreach efforts will serve to **EXPAND the Voices of PROPEL**. This will support additional patient/caregiver enrollment, increasing from the initial 4-center **PROPEL** study to a more inclusive, province-wide initiative to **EXPAND the Voices of PROPEL**.

As in the founding **PROPEL** study, **EXPAND the Voices of PROPEL**, patients and caregivers self-identify for participation and provide informed consent through the University of Calgary's POET-SHIELD electronic platform and receive tailored questionnaires assessing well-being and health-

related quality of life via a secure REDCap online platform. (Figure 1) PROMs used in the PROPEL study were selected in consultation with patient/caregiver partners to address the most relevant issues related to global functioning and caregiving in contemporary lung cancer management. (Figure 2).

EXPAND the Voices of PROPEL would focus resources on identifying additional oncologists in Albertan community cancer centers, patient/caregiver ambassadors, and community spaces to reach potential participants who are representative of diverse Alberta communities (Indigenous, rural, remote, Canadian newcomers, etc.), and concentrating efforts on recruiting and building cohorts within the **EXPAND the Voices of PROPEL** study that accurately reflect the diverse population of Albertans impacted by advanced lung cancer, and continue to build on the original **PROPEL** study objectives. (Figure 3)

Anticipated Results & Conclusions:

The **EXPAND the Voices of PROPEL** project seeks to recruit an additional 100 patients and 100 caregivers from regional and community cancer care centers, building on a similar recruitment goal from the original **PROPEL** study. Through project expansion, the goal is to support a province-wide initiative to raise awareness about patient-reported outcomes (PROMs) in precision medicine and integration of these measures into the clinical practice of personalized medicine. The project also aims to increase awareness through the recruitment of additional patient and caregiver advocates, community leaders, and local initiatives to promote lung cancer awareness, prevention, and participation in screening programs for high-risk Albertans. Twelve months after launch, the project will assess feasibility, including recruitment rates, questionnaire completion, and demographic and socioeconomic data to evaluate its reach across Alberta's diverse population. It will also examine if the project effectively engages equity-seeking communities and will inform strategies for increased inclusivity and improved patient-centered lung cancer services in Alberta. This project, the first to collect PROMs at the population level for people impacted by advanced lung cancer, will also assess the feasibility of online consent and data collection, and uncover potential barriers or successes in data capture to improve and inform future efforts.

Challenges:

The primary challenge for this project is raising participant awareness. While PROMs are generally well-received by patients to share their experiences, this has not been specifically studied within Alberta's lung cancer community, especially among both patients and caregivers. Reaching all geographic areas and societal groups may be challenging and requires additional resources, such as those which funding from a Lung Ambition Award would allow. Overcoming these obstacles would require project coordination to implement strategies like targeted outreach, culturally aware methods, involving community leaders to promote the project in local spaces, and exploring options like survey language translation for improved accessibility.

Knowledge Mobilization:

Throughout the course of the study key themes from participant data will be summarized and shared publicly in an accessible way for lung cancer patients, their supports, advocacy groups, healthcare providers, the academic community, and policymakers. (Figure 4) This will help keep the focus on the patient experience and encourage ongoing inclusion of patient voices in precision lung cancer care. Additionally, peer-reviewed abstracts or manuscripts will be produced to validate findings, gather feedback on methods, and further the discussion on implementing PROMs in the lung cancer community.

Tables and Figures:

Figure 1:

EXPAND the Voices of PROPEL Study Participant Flow and Study Design

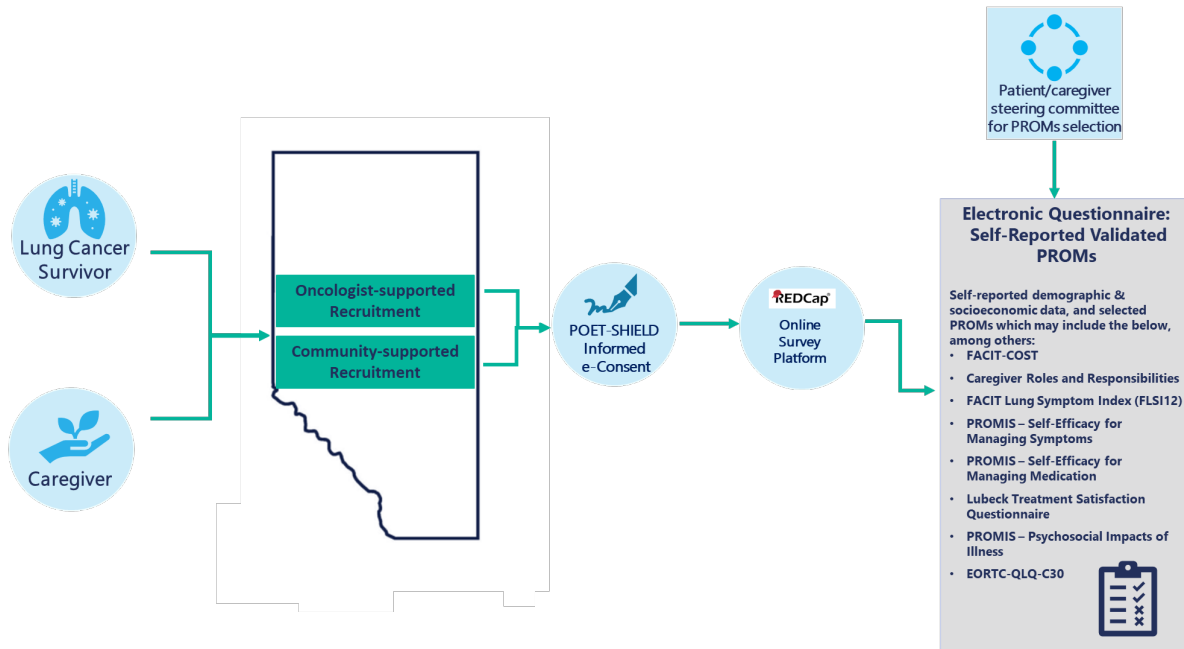


Figure 2:

EXPAND the Voices of PROPEL Patient-Reported Outcomes Collection

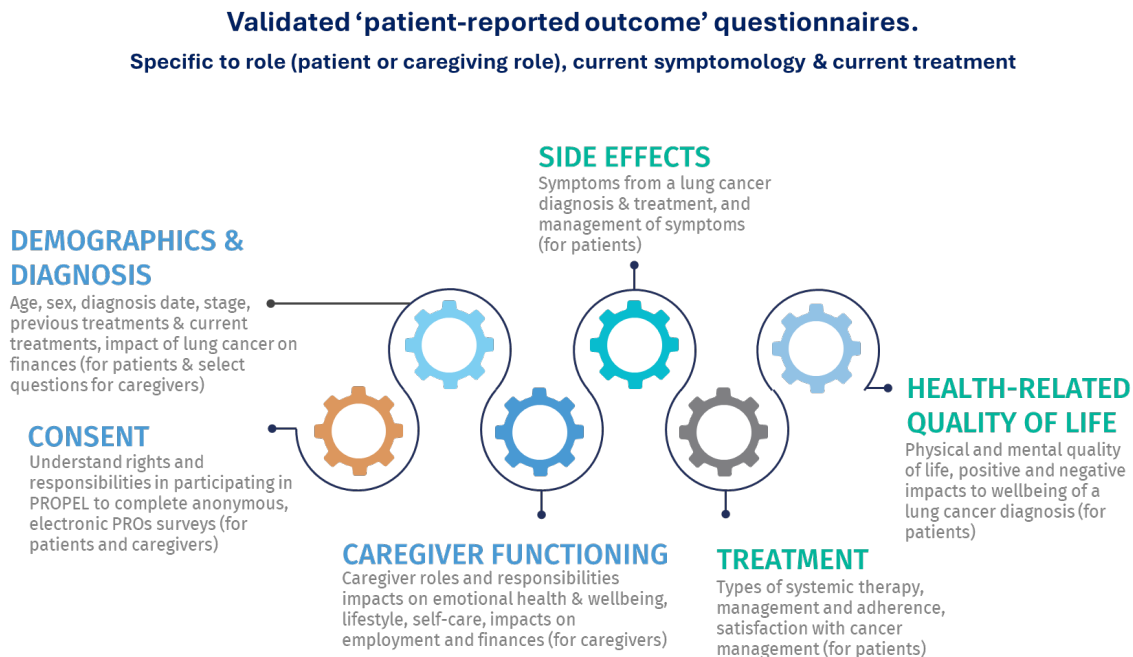


Figure 3:

PROPEL Objectives

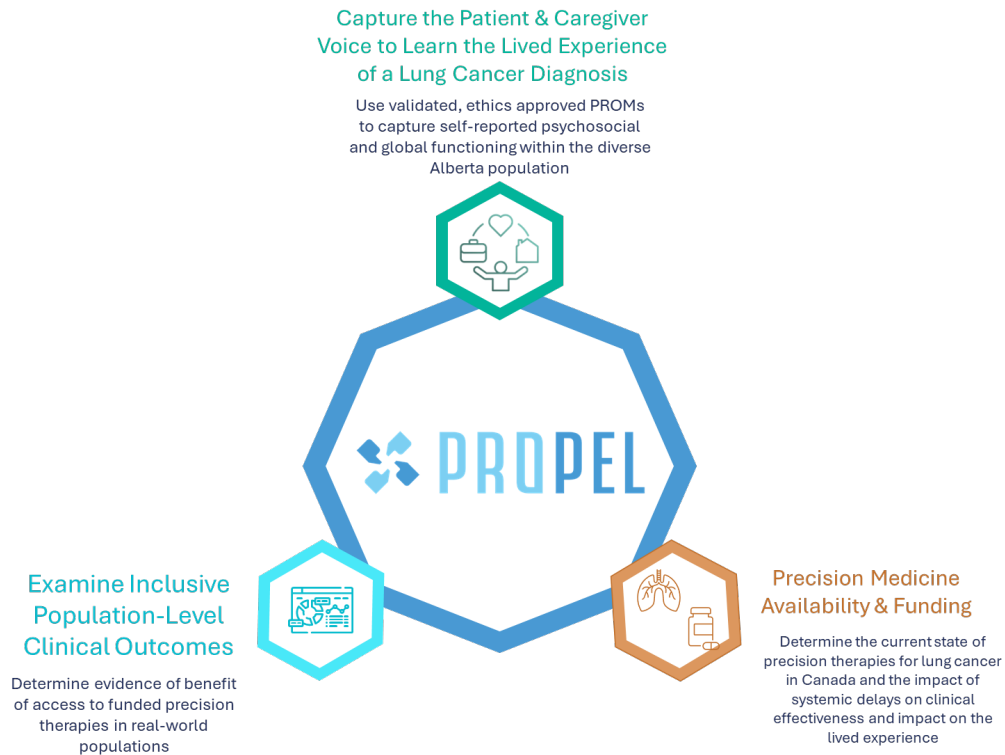
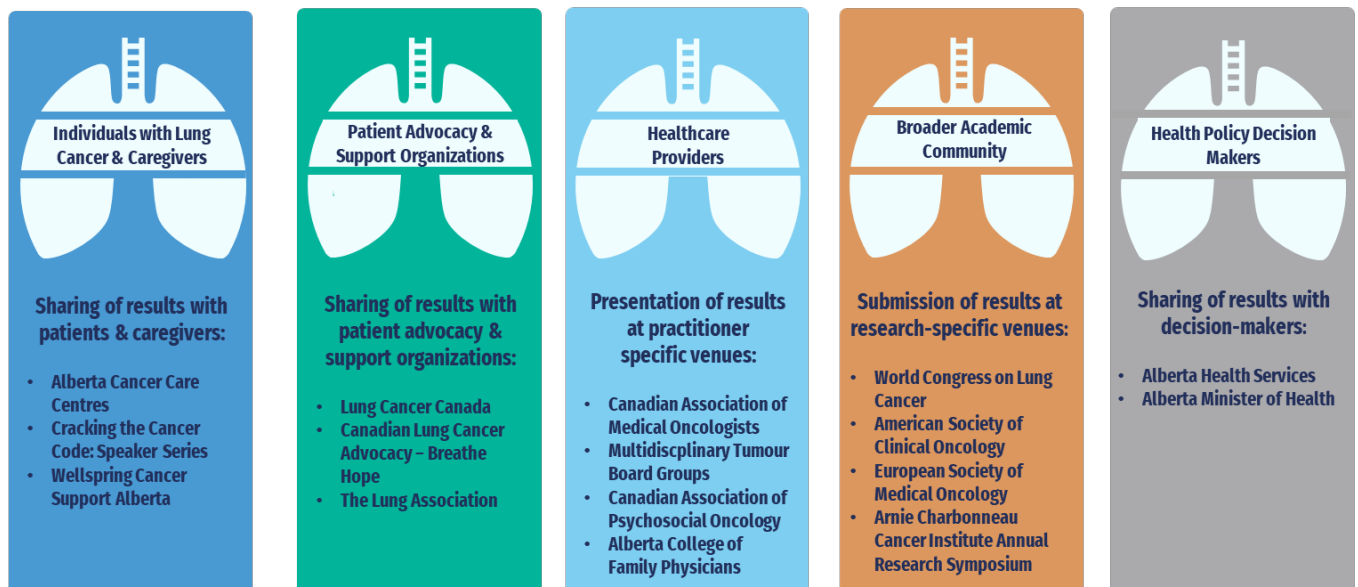


Figure 4:

EXPAND the Voices of PROPEL Knowledge Dissemination



Impact Statement

Capturing the patient lived experience of lung cancer management is often limited to symptom-focused data in the clinical setting to identify patients at immediate risk of harm. The spectrum of other impacts of an advanced lung cancer diagnosis and management at the individual and caregiver/community level are not routinely captured and addressed as intentionally as treatment-related symptoms are. However, life experiences which create negative determinants of health, including socioeconomic and mental health disorders, arising or exacerbated by a lung cancer diagnosis, have been shown to be associated with increased mortality. To date, the lived experience has not been explored or collected in a way which yields decision-making grade data in Alberta, nor has the use of PROMs for both patients and caregivers been utilized to identify inequities and unmet needs in the context of advanced lung cancer.

EXPAND the Voices of PROPEL is an impactful and innovative study, building off the original **PROPEL** which will capture the lived experience- inclusive of a wide scope of measures of wellbeing and global functioning- through a unique study design using a self-referral model, pre-existing electronic consenting infrastructure, and online PROMs distribution. This method improves accessibility and facilitates anonymized data collection outside of the healthcare system providing participants the opportunity to freely share lived experience in a private context, removing barriers to disclosure which could occur if situated within the healthcare setting, or using a less private means of PROMs collection.

While PROMs capture within the healthcare system has been integrated into standard of care practice, in this context PROMs are limited in scope, patient-focused, and designed to capture situations which have direct and immediate impact on patient care. Collection of PROMs less focused on serious symptomology or distress screening are absent within the healthcare setting, and those which exist tend to be narrow in scope, available only to patients treated within the clinical trial setting, or short-term initiatives available only to patients involved in clinical trials or affiliated with large academic cancer care centers. The design of the **EXPAND the Voices of PROPEL** study is aimed towards improving accessibility and facilitates anonymized data collection outside of the healthcare system and provides participants the opportunity to freely share lived experience in a private context, removing barriers to disclosure which could occur if situated within the healthcare setting, or using a less private means of PROMs collection.

Understanding the role and feasibility of PROMs capture for both patient and caregivers is an important first step in their incorporation as a component of precision/personalized medicine. Knowledge gains from a study like **EXPAND the Voices of PROPEL** have the potential to impact healthcare policy as well as informing the creation of supports within the community and social systems which can serve to augment and protect patient quality of life and support the wellbeing of caregivers and wider community impacted by this all too common and devastating diagnosis.

Public Summary

Living with lung cancer can be very hard for people. They might have trouble enjoying everyday activities or socializing with others. Many people with lung cancer also feel sad, anxious, or have a hard time talking about their fears and feelings with family, friends, doctors, or others. The disease and its treatments can cause physical symptoms that make it difficult for people to do things like cook, clean, or participate in activities they once enjoyed. They may also struggle to go to work or keep up with their usual routines. Family members and friends of people with lung cancer may also feel worried, sad, or scared. Taking care of someone with lung cancer can be physically and emotionally challenging for them too.

To understand how lung cancer impacts the well-being of patients and their caregivers, surveys called 'patient-reported outcome measures' (PROMs) are used. These surveys gather information on daily experiences and quality of life, including physical, social, emotional, and psychological well-being. PROMs help provide a deeper understanding of what it's like to live with lung cancer or care for someone with the disease. This study will explore whether collecting PROMs data online is feasible and effective in assessing the well-being and overall functioning of those affected by a lung cancer diagnosis.

Originally, the **PROPEL** project, which stands for (**Patient Reported Outcomes in People Experiencing Lung Cancer**), was designed to provide online PROMs to people in four Alberta cities (Calgary, Red Deer, Edmonton and Grande Prairie). To capture the experience of lung cancer from all Albertans, we want to grow the project and **EXPAND the Voices of PROPEL** in order to **E**mpower patients, understand the lived **eX**perience, **P**romote **A**wareness, and support **N**avigating the lung cancer journey, with the **D**evelopment of resources. The **EXPAND the Voices of PROPEL** project will open up PROMs collection to people attending any one of Alberta's 17 cancer care centers.

The surveys can be accessed online, using a computer, tablet or cellphone to answer them. Anyone who has lung cancer or who is a friend or family member to someone with lung cancer can do the surveys. The surveys can be done anytime, and from anywhere that has internet access. The surveys are easy to do, much like doing a survey or poll on Facebook or Instagram. People who consent to doing the surveys will be asked to answer questions about their experience of living with lung cancer or what caring for a person with lung cancer has been like.

This data collection method can help identify challenges unique to certain groups in Alberta, such as differences in age, personal identity, finances, disability, location, culture, or being a newcomer to Canada. It ensures patients and caregivers can share their experiences in a way that respects their privacy and makes them feel comfortable. The study is accessed online and uses simple, inclusive language and accessible features, like large text, so people from different backgrounds and locations can easily participate. By reaching out to people across Alberta with different life situations, the research can gather a wide range of experiences. This method is especially helpful for those who may feel uncomfortable sharing their experiences with family, friends, or doctors, and can help create better support for people who struggle to access care, especially in rural areas or those with fewer resources.

By identifying the greatest challenges for people with lung cancer and their caregivers the **EXPAND the Voices of PROPEL** works to identify ways which can make the experience of lung cancer better finding ways to improve well-being and quality of life for Albertans impacted by lung cancer.

Budget

Estimated Study Budget	
Patient Engagement Coordinator - 0.6 FTE including Salary, Pension and Benefits	\$46,800
Knowledge Translation & Sharing	\$3,200
TOTAL	\$50,000

Investigator/CO-I CV

Submitted as separate document

Statement of Support from Institution



UNIVERSITY OF CALGARY
CUMMING SCHOOL OF MEDICINE
Department of Oncology



**Cancer Care
Alberta**

Don Morris, MD, PhD, FRCPC
Facility Medical Director, Tom Baker Cancer Centre
Head, Dept of Oncology, University of Calgary
Head, Clinical Department of Oncology, Calgary Zone
Cancer Care Alberta, Alberta Health Services
Medical Lead, Arthur JE Child Comprehensive Cancer Centre
1331 29th St NW, Calgary, AB T2N 4N2
Tel 403 521 3701 Fax 403 944 2331

July 12, 2024

To Whom It May Concern:

Re: Marathon of Hope Patient Voices in Research Initiative Grant

As Professor and Head, Department of Oncology, University of Calgary, and Facility Medical Director of the Tom Baker Cancer Centre, Alberta Health Services, I wish to express my support for the PROpel Study – Patient Reported Outcomes of People Experiencing Lung Cancer project. The Department of Oncology and the Tom Baker Cancer Centre aim to reduce the impact of cancer on all Albertans and provide expert care and support for patients from symptom onset to survivorship.

Dr. Navani's proposal seeks to involve consenting lung cancer patients to share their experience via a questionnaire with the aim of making the connection between different outcomes and precision medicine. The long term goal is to provide evidence that will allow more targeted therapy and immune therapy to become a part of the standard of care.

I strongly support this exciting project . Please do not hesitate to contact me if you have any questions.

Sincerely,

Don Morris MD, PhD, FRCPC
Professor and Head, Department of Oncology, Cumming School of Medicine, University of Calgary
Facility Medical Director, Tom Baker Cancer Centre
Department Head, Clinical Department of Oncology, Calgary Zone, AHS
Medical Lead, Arthur JE Child Comprehensive Cancer Centre
Associate Senior Medical Director, Cancer Care Alberta, AHS

July 16, 2024

Dr. Vishal Navani
Principal Director - Glans-Look Research Program
1331 29th Street NW, Calgary, AB
Calgary, AB T2N 4N2

Dear Dr. Navani,

Thank you for introducing us to the PROpel Study – Patent Reported Outcomes of People Experiencing Lung Cancer project. This project aims to capture the patient voice alongside the examination of inclusive population-level clinical outcomes and inform on the state of precision therapeutic availability in Canada.

Our flagship cancer-agnostic study POET-SHIELD is well suited to provide an infrastructure to allow the delivery of patient-reported outcome measures (PROMs) questionnaires and the collection of clinical outcomes. The POET program has experience evaluating these same outcomes through PROgress Tracker, a similar study sponsored by Breast Cancer Canada.

As Scientific and Clinical Leads of the Precision Oncology and Experimental Therapeutics program at the University of Calgary, we are excited to partner with the Glans-Look team in support of this study. We look forward to helping fulfill unmet needs by identifying potential gaps in care, disparities in precision therapy accessibility, and informing evidence-based decision making for patients experiencing lung cancer.

Sincerely,



Pinaki Bose, PhD
Scientific Lead – POET Program
Assistant Professor Biochemistry & Molecular Biology
Cumming School of Medicine | Oncology
3330 Hospital Dr NW
Calgary, Alberta, Canada T2N 4N1
Telephone (403) 220-8507



Steven Yip, MD, MSc, FRCPC
Medical Lead – POET Program
Clinical Assistant Professor
Medical Oncologist
Cumming School of Medicine | Oncology
1331 29th Street NW
Calgary, AB, Canada T2N 4N2
Telephone (403) 521-3347