FY2021 New
Assembly/Committee Project Application

Submitter: **Donald Sullivan**

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Collaboration: There will be opportunities for other organizations to co-sponsor the document. The ATS prefers that the project not be discussed with potential co-sponsoring organizations until the project has been approved because premature discussions may jeopardize a final agreement. All negotiations for collaboration will be handled by ATS staff following project approval.

SECTION I - GENERAL PROJECT INFORMATION

* 1. ATS PROJECT TITLE:

An Official ATS Policy Statement: Palliative Care Early in the Care Continuum among Patients with Respiratory Disease with a Focus on Chronic Obstructive Pulmonary Disease, Interstitial Lung Disease and Lung Cancer

* 2. PROJECT PRIMARY ASSEMBLY:

Behavioral Science and Health Services

* 3. ATS SECTION:

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* 4. ATS COMMITTEE SUBMITTING PROJECT APPLICATION:

Patient and Family Education Committee

* 5. What official ATS document will be developed as part of this project?

Policy Statement

* 6. Can the project move forward as a virtual project if necessary?

Yes

SECTION II - RELEVANCE to ATS

PROJECT DESCRIPTION

* A. Clearly and concisely describe the project's goals, objectives, and relevance/importance to the ATS. Goals and objectives should be focused and feasible to achieve. Do NOT include your meeting agenda here. If you are proposing a clinical practice guideline, this section should include your PICO question(s). (maximum of 6 questions are permitted)

The only policy statement on palliative care by the ATS was developed in 2007 and published in 2008. (1) Since the publication of this statement 12 years ago, palliative care has significantly expanded as a field beyond hospice and end-of-life care. Data in cancer, heart failure, and critically ill populations has demonstrated significant improvements in quality of life (QOL), symptom burden, healthcare costs, and even survival associated with timely integration. (2) Unfortunately, palliative care remains poorly integrated into the routine care of patients with respiratory disease or is integrated too late in the illness trajectory, often at the very end of life in the intensive care unit (ICU), to provide meaningful benefits. (3-8) In light of recent advances in the evidence and the growing population of seriously ill patients with respiratory disease who would benefit from palliative care, an update to the 2008 ATS statement is urgently needed.

Despite increased recognition of the importance of palliative care in respiratory disease, evidence suggests implementation in clinical settings remains poor. (3-16) Instead, high-intensity end-of-life care is delivered which is often inconsistent with the preferences and values of patients and their families, (17, 18) and does not represent high quality or high value care. Pulmonary and critical care medicine clinicians are well-positioned to integrate palliative care into their routine clinical practice given their significant role in the care of patients with respiratory diseases across the care continuum (i.e., from ambulatory settings to the Intensive care unit (ICU)). Additionally, few medical specialties are confronted with palliative and end-of-life care as commonly as pulmonary and critical care clinicians as respiratory diseases contribute significantly to patient morbidity and mortality. Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death, lung cancer is the leading cause of cancer-related mortality, and interstitial lung disease (ILD) prevalence and disease morbidity is

increasing (19). Therefore, the ATS should be at the forefront of establishing best practices, policies, and research priorities within the field of palliative care for patients with respiratory disease.

Patients with lung cancer suffer from significant symptom burden and high disease-related mortality making them ideal candidates for integrated palliative care. (20-22) The integration of palliative care in lung cancer could serve as a potential model for patients with non-cancer respiratory disease given the available evidence in lung cancer. (23-26) Palliative care is underutilized in COPD as noted in the ATS's latest disease update document. (27) Other studies have similarly highlighted the need for more efforts to offer palliation in COPD. (28) ILD prevalence is low, however, it is increasing (29) and these patients suffer from considerable symptom burden and reduced QOL. (30, 31) As a result, the National Institute of Care Excellence has highlighted the need for more palliative care among patients with ILD. (32) Clearly, the ATS should have a pivotal role in providing policy recommendations on palliative care among these patient populations, as they affect a significant proportion of the patients cared for by members of the ATS.

The previous ATS policy statement pre-dated most of the substantive research and knowledge in the field and serves as an introduction to palliative care in pulmonary and critical care medicine. Now there are calls for increased, earlier integration of palliative care, with disease-specific evidence-based recommendations from subspecialty palliative care societies. (11-13) Additionally, the COVID pandemic has highlighted unmet palliative care needs and opportunities for innovation among those with respiratory disease by increasing the emphasis on advance care planning and timely integration of palliative care. (33, 34) A reliable ATS resource focused on palliative care could help mitigate undesirable consequences such as patient and family harm, missed opportunities for high-quality care, and increased healthcare costs. (2) Additionally, there is emerging data on novel approaches to integrating primary (i.e., palliative care delivered by non-palliative care specialists) and specialty palliative care in pulmonary and critical care medicine. (35) The ATS can help lead and shape the international discussion regarding palliative care use with thoughtful, timely, and carefully crafted positions on this critical topic.

Palliative care is recognized as an important complementary approach with meaningful patient benefits, especially when delivered earlier in the disease trajectory. (36) Therefore, there is a substantial need for the ATS to expand their position on the integration of palliative care for three important reasons: i) critical advances in palliative care research have occurred during the past 12 years re-framing the conceptual model of palliative care and its integration in practice; ii) despite advances in palliative care it remains underutilized among patients with respiratory disease, as studies demonstrate intensity and costs of care at the end-of-life are increasing; (37, 38) and (iii) palliative care research priorities need to be established to continue to develop innovative solutions among those with

respiratory disease.

This project will assemble a multidisciplinary, international ATS Task Force on Palliative and End-of-Life Care that will generate an updated, re-framed and expanded evidence-based policy statement on the integration of palliative care into the management of patients with respiratory disease with a focus on COPD, ILD, and lung cancer, as models for integration of palliative care in respiratory disease. The taskforce will form the foundation for a palliative and end-of-life care working group, and the statement will have three main goals: (i) to encourage timely, integrated palliative care in respiratory disease, highlighting current evidence; (ii) to review and promote innovative primary and specialty palliative care delivery models in pulmonary and critical care medicine; and, (iii) to advocate for research to improve the quality and availability of palliative care in pulmonary and critical care medicine.

This project has the following specific aims: 1) Synthesize an updated and expanded evidence-based policy statement presenting ATS's principles and values of palliative care for use in respiratory disease with a focus on COPD, ILD and lung cancer; 2) Review and discuss alternative models for integrating primary and secondary palliative care into the care of patients with respiratory disease; and 3) Identify evidence gaps and research priorities that reinforce the need for innovative palliative care solutions to address the needs of patients with respiratory disease and their caregivers.

A seamless and important progression of this proposed project would be a future workshop proposal (or similar ATS activity) to establish the potential roles for pulmonary and critical care clinicians in the provision of primary palliative care by developing enhanced training opportunities for clinicians. There is increasing evidence for innovative models of primary palliative care integration and specialty palliative care for patients with respiratory disease, including increased training in primary palliative care, implementation of multidisciplinary breathlessness clinics, and embedded palliative care specialists in pulmonary clinics. (39, 40) The provision of primary palliative care is especially important as a 1% absolute growth in palliative care specialists is expected in the next 20 years, far outpaced by the needs of the aging U.S. population. (41, 42) Palliative care also represents a core ACGME competency in pulmonary and critical care medicine training. Unfortunately, few pulmonary and critical care medicine fellowship programs have developed curricula. (43-45) Therefore, it is essential for the ATS to support the development of primary palliative care training opportunities such as webcasts, online modules, or a web-based toolkit. These modules would improve inter-professional training and education specifically among pulmonary and critical care medicine fellowship trainees and pulmonary and critical care medicine practicing clinicians, including nurses, physician assistants, and respiratory therapists. This future project proposal would also enhance dissemination and uptake of the ATS's expanded policy statement on palliative care.

1. Lanken P. An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses. AJRCCM. 2008 Apr 15;177(8):912-927.
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6. Fenstad ER. Physician attitudes toward palliative care for patients with pulmonary arterial hypertension: results of a cross-sectional survey. Pulm Circ. 2014 Sep; 4(3): 504–510.
7. Ruggiero R, Reinke LF. Palliative Care in Advanced Lung Diseases: A Void That Needs Filling. Ann Am Thorac Soc. 2018 Nov;15(11):1265-1268.
8. Wachterman MW, Pilver C, Smith D, et al.: Quality of end-of-life care provided to patients with different serious illnesses. JAMA Intern Med 2016;176:1095–1102.
9. Bajwah S. Palliative care and interstitial lung disease. Curr Opin Support Palliat Care. 2017 Sep;11(3):141-146.
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B. Describe any related ATS / non-ATS activities relevant to your project.

Drs. Iyer and Reinke co-chaired a scientific symposium entitled, “Palliative Care in Chronic Respiratory Disease – A State of the Science” that was well received at the ATS 2020 Virtual Conference.

Dr. Sullivan has also submitted a scientific symposium entitled, "The Future of Palliative Care in Respiratory Medicine: Delivery Models, Disparities and Pandemics" for consideration for the 2021 ATS International Conference.

* C. How does this project relate to health equality? How will health equality be addressed in this project?

Health equality is defined as equal access to available care and that equal quality of care exists for everyone. (1) Among patients with respiratory disease, there are significant health disparities relating to the inadequate use and provision of palliative care. (2-6) This situation persists despite evidence that palliative care enhances the overall quality of care and QOL for patients, and maybe even improves survival. (7-10) This project will specifically address the lack of integration of palliative care into pulmonary medicine highlighting inequality in integration and utilization that exist in current practice. We have recruited experts in heath disparities, Drs. J. Daryl Thornton and Kimberly Johnson, to help lead the discussion of strategies toward reducing health inequalities in palliative care among patients with respiratory disease. In addition, this project will identify the current gaps in the palliative care literature that contribute to the persistence of health inequality as it relates to the delivery of palliative

care.

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7. Kavaliertos D. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. JAMA. 2016;316(20):2104-2114.
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* D. All applicants must review a document development video (https://www.thoracic.org/members/assemblies/about/assembly-project-application-resource-center.php) and set of document-development vignettes prior to submitting this application.

Yes, I have review the document development video

E. FOR CME EDUCATIONAL PROJECTS/PRODUCTS ONLY: FOR MORE INFORMATION PLEASE SEE INSTRUCTIONS. PLEASE DESCRIBE THE FOLLOWING:

☑ Not Applicable

SECTION III - METHODOLOGY

* A. Please describe the approach for creating the document. This section should demonstrate that the scope of work can be completed on time. There should be a clear plan for how tasks, such as paper writing, will be completed (e.g., how will writing tasks be divide? what are the opportunities for the committee to provide feedback?). Please include why you feel the selected document type is the most appropriate.

The proposed project will be completed in three phases: 1) pre-meeting, 2) meeting, and 3) post-meeting

to produce an updated and expanded ATS policy statement on the integration of palliative care among patients with respiratory disease with a focus on COPD, ILD, and lung cancer. A policy statement is the most appropriate document as it presents the positions of ATS on issues that pertain to health care delivery and health policy. We will assemble a diverse, inter-professional working group of international experts including early career professionals, patients/caregivers, and underrepresented participants. The project working group also represents gender and non-physician healthcare professional diversity. We have allotted ample time to achieve the project aims and produce a comprehensive, impactful policy statement in partnership with stakeholder societies after consultation with the ATS Chief of Documents and Patient Education, Dr. Kevin Wilson. A clear plan for all proposed project tasks is detailed below:

1) **Pre-Meeting**: The steering committee will be composed of two junior (Drs. Sullivan and Iyer) and one senior co-chair (Dr. Reinke) with an ATS-past president, Dr. Curtis, acting as senior advisor. We have assembled a diverse, inter-professional (i.e., nurses, respiratory therapists, physicians, social worker, sociologist and a pharmacist) panel of international experts from relevant disciplines. In order to achieve the greatest potential impact in the field, and under the direction of ATS staff, we will invite palliative care experts from national stakeholder palliative care societies [e.g., American Academy of Hospice and Palliative Medicine (AAHPM), Hospice and Palliative Nurses Association (HPNA), Center to Advance Palliative Care (CAPC)] committed to the management of patients with respiratory disease. We anticipate collaborating societies may wish to appoint additional working group participants.

The co-chairs will provide key literature and prepare introductory materials to distribute to the remainder of the project participants by March 2021, two months prior to the in-person ATS conference meeting. The literature summary will include: a recent systematic review and meta-analysis of palliative care interventions in adults with life-limiting illness, a recent article reviewing the existing gaps in evidence for palliative care research in pulmonary disease and critical illness, and other relevant, disease-specific literature that summarizes the current evidence in pulmonary and critical care medicine published prior to the meeting. (1-7) Additionally, to maximize breakout group efficiency and productivity, breakout group facilitators will participate in two teleconferences with the steering committee in the spring (March and April) prior to the in-person meeting where we will review group structure/function and develop briefing packets for the breakout groups which will consist of relevant scientific articles, group objectives, and suggestions for reporting group findings.

If this project is approved and funded, we will apply to the Documents Committee for permission to seek co-sponsorship of the project. We have consulted with Dr. Kevin Wilson who, as the ATS Chief of Documents, will reach out to colleagues at complementary palliative care professional societies such as the American Academy of Hospice and Palliative Medicine (AAHPM), Hospice and Palliative Nurses Association (HPNA), and the Center to Advance Palliative Care (CAPC) and invite them to co-sponsor the

project. As an initial offer, the ATS will invite the potential co-sponsors to appoint two representatives to the working group, to peer review the document, and to approve the final version of the document. After brief negotiations, assuming agreement can be reached, a memorandum of understanding (MOU) will be signed by all co-sponsoring organizations. This MOU will describe the project leadership, panel composition, budget, peer review process, approval process, publication site, and plans for dissemination. The project participants will abide by the terms of the MOU.

In a demonstration of feasibility of achieving co-sponsorship of this document, several members of the working group are current and prominent members of the suggested collaborating societies. Dr. Reinke serves on the Board of Directors for the HPNA. Additionally, Drs. Iyer and Sullivan, are co-chairs of a new forum they founded within AAHPM on palliative care in chronic respiratory disease, which can further support collaboration. We recognize that there are challenges to co-sponsorship of ATS documents, and have therefore, been consulting with Dr. Wilson who has advised us regarding the process and timeline for pursuing co-sponsorship. We believe the benefits of collaboration on this document given the inter-professional nature of palliative care far outweigh the concerns.

The steering committee composed of the project co-chairs and project advisor will initially convene by telephone to define the agenda, develop a draft outline for the report, and confirm all participants of the working group to take place at the ATS 2021 International Conference (or virtually). The working group will be composed of 19 ATS members, 6 external content experts including some suggested members from the aforementioned co-sponsoring organizations, and 2 patient/family PAR representatives. PAR representatives who have or are a family caregiver to a patient with an advanced respiratory disease (COPD, ILD, or Lung CA) and have prior experiences with palliative care will be sought. The working group is primarily composed of members of the BSHSR, Nursing, and Thoracic Oncology assemblies- given their interest in the statement topic. The Nursing and Thoracic Oncology assembly planning committees have expressed support for the project as it dovetails with their programmatic priorities. Additionally, the Patient and Family Education Committee endorses the project in concept as it is patient- and family-centered and there is the potential to develop companion patient and family educational materials closely associated with the project. The working committee meeting at ATS 2021 will review the available literature and conceptual frameworks, solidify the goals of the document, establish the writing committee members, and outline specific dates for the remainder of the project timeline.

I. Pre-Meeting Agenda (Jan-April 2021)

a. Obtain co-sponsorship from AAHPM, HPNA, and CAPC

b. Invite and confirm participants

c. Confirm speakers and breakout group facilitators; assign participants to breakout groups based on content expertise and/or interest

d. Review agenda with participants and solicit feedback
e. Identify members of writing committee
f. Distribute key readings and introductory materials to project participants
g. Breakout group leaders formulate plans for sessions and create briefing packets
h. Develop a draft outline for the report
i. Review/manage participants' conflicts of interests

2) **Meeting**: Agenda for Working Group Meeting

I. Main Themes for In-Person Working Group Meeting (May 2021):

a. Discuss the current state of the science with a focus on the evidence basis for integration of palliative care into routine care for patients with respiratory disease.

b. Discuss how utilization of palliative care impacts the quality and value of care patients receive.

c. Discuss the importance of an inter-professional approach and the roles of pulmonary and critical care clinicians in providing primary palliative care (i.e., palliative care delivered by non-specialists) and in consultation with palliative care specialists

d. Review evidence base for alternative models for integrating primary and specialty palliative care into the care of patients with respiratory disease.

i. Models for embedded palliative care specialists or stand-alone palliative care clinics.
ii. Multidisciplinary breathlessness clinics and other innovative models.

e. Examine aspects of palliative care that specifically relate to clinical practice among pulmonary and critical care clinicians, including the following key areas:

i. The interaction between palliative care provided concurrently with other medical therapies (i.e., targeted chemotherapy, immunotherapy, ILD disease-modifying therapy)
ii. Examine the importance, timing and resources available to improve prognostic awareness in respiratory disease in ambulatory settings (i.e., code status discussions, advance care planning, and establishing goals and limitations of care).

II. Working Group Meeting Agenda (ATS 2021)

In an effort to introduce the main themes to the participants (see detailed meeting agenda below), the meeting will begin with three speakers who will present an overview of the five primary themes followed by a brief discussion period where participants' feedback will be elicited in round-table discussions. During the first break, the co-chairs will organize the major discussion points to determine if modifications to breakout group session objectives are needed. Next, concurrent small breakout group sessions will be conducted where group facilitators (with one designated lead) are pre-assigned to small groups based on their expertise and interests. PAR representatives will also participate in small groups based on their interests. During these group sessions the co-chairs who are not facilitating will float between groups to

help support the discussion. Breakout groups will be provided briefing packets which are intended to provide a framework for group activities to maximize productivity. Briefing packets (created by group facilitators in consultation with project co-chairs) will provide a framework for the breakout groups which will consist of relevant scientific articles, group objectives, and suggestions for reporting group findings. Breakout group specific objectives will include: i) summarizing the gaps in the literature and their importance, ii) discuss how these gaps can be overcome, and iii) write an outline to be reported back to the broader group that will inform the creation of a policy statement. Group facilitators will be expected to record and synthesize breakout group discussions and subsequent broader group discussions in an outline format. At least one facilitator from each breakout group will be part of the writing group committee helping to create the policy statement by incorporating outline content.

Finally, the meeting will conclude with a summation session where we identify areas of agreement and dissent within our major themes using consensus based methodology (i.e., modified Delphi approach). A modified Delphi approach will allow the co-chairs to generate a comprehensive list of common themes that address our primary aims. Co-chairs will distribute the list to the workshop participants to reach consensus for the key elements of the framework. Each working group participant will be asked to rate the importance of each item, as well as to suggest potential additional items. Consensus will be considered reached when 80% of the participants strongly agree that an element should be included/excluded. If agreement is not reached in the first round, or where new suggestions are added, then this item will be carried forward to a second round along with an aggregated summary of the first round results. Participants will again rank the items and a final list will be generated based on the order of importance. A finalized list of common themes, developed by consensus based methodology, will be distributed via email to the full working committee for review immediately following the ATS 2021 meeting. The overall goal of this project is to bring together a diverse, multidisciplinary group of international participants to synthesize a consensus policy statement of the principles and values of palliative care for use in pulmonary and critical care medicine with a particular focus on COPD, ILD and lung cancer.

ATS 2021, Face-to-face or virtual meeting agenda:

a. Invited Speakers: 8:30 to 10:00 am (of note, 3 of 4 invited speakers are from the ATS)

i. ATS PAR Representative: Opening talk to motivate group and describe importance of this topic from a patients or family caregiver perspective

ii. Donald Sullivan: State of the evidence: Palliative care integration in respiratory disease using lung cancer as a model

iii. Diane Meier: A global imperative: Palliative care represents high quality and value care among patients with respiratory disease

iv. Anand Iyer: Translating theory into practice: Models for primary and secondary palliative care delivery in diverse clinical settings

b. Break: 10:00 to 10:15 am

c. Breakout Session I: 10:15 to 11:30 am

i. Each breakout group will identify important issues, summarize evidence and gaps in evidence, and discuss how these gaps can be overcome

ii. Breakout Groups 1-3

1. Innovative system-level interventions in palliative care delivery among patients with respiratory disease: Matthew Maddocks (lead) and Natasha Smallwood, Facilitators

2. Comprehensive symptom management in respiratory disease: Lynn Reinke (lead) and Mary McPherson, Facilitators

3. Outcome measurement and metrics for success in palliative care: Erin Kross (lead) and Christopher Cox, Facilitators

d. Report back to entire group: 11:30 to 12:30 pm

e. Break for lunch: 12:30 to 1:30 pm

f. Breakout Session II: 1:30 to 2:45 pm

i. Each breakout group will identify important issues, summarize evidence and gaps in evidence, and discuss how these gaps can be overcome

ii. Breakout Groups 4-6

4. Cutting-edge strategies toward reducing health disparities in palliative care among patients with respiratory disease: J. Daryl Thornton (lead) and Kimberly Johnson, Facilitators

5. The evolution of palliative pulmonary and critical research and future approaches: Katherine Courtright (lead) and Christiane Hartog, Facilitators

6. Lasting lessons in future palliative care planning from the pandemic: J. Randall Curtis (lead) and Helen Sorenson, Facilitators

g. Report back to group: 2:45 to 3:45 pm

h. Summation Session, Work Plan for Document Writing: 3:45 to 5:00 pm

3) **Post-Meeting**: Following the meeting at ATS 2021, a series of teleconferences will be held between June 2021 and March 2022 between members of the writing committee to further refine the conclusions of the group and produce a policy statement summarizing our findings. The writing committee will be composed of the 3 co-chairs along with 6 key small group facilitators (1/breakout group) and at least one PAR member. The sections will then be sent to the co-chairs, who will collate the sections into a single manuscript by September 2021. We will use subsequent teleconferences to address comments and suggestions for revisions. The manuscript will be reviewed and revised by the full committee in an iterative fashion between October 2021 and March 2022. Finally, our goal is to have the manuscript

submitted for peer review by the end of March 2022. The extended timeline for document preparation has been suggested in conjunction with Dr. Wilson to account for any potential delays in co-sponsoring societies' peer review of the document and approval of the final version.

As described, the key deliverable from this meeting will be the creation of a policy statement that will summarize consensus discussions and provide guidance on the integration and implementation of palliative care in respiratory disease. It will serve as a practical, inter-professional reference document for members of the ATS and larger community who practice pulmonary and critical care medicine. The project co-chairs will engage in a broad dissemination plan for this policy statement in accordance with ATS guidelines to educate fellow ATS members and the larger community of pulmonary and critical care clinicians. We will also form a Palliative and End-of-Life Care Interest Group (co-chaired by Drs. Iyer and Sullivan) within ATS which will continue to meet yearly and host conference calls to plan future palliative care focused proposals such as symposia and future documents. As evidence of Interest Group sustainability, Dr. Iyer chaired a scientific symposium entitled, "Palliative Care in Chronic Respiratory Disease – A State of the Science" that was well received at the ATS 2020 Virtual Conference. Dr. Sullivan has also submitted a scientific symposium entitled, "The Future of Palliative Care in Respiratory Medicine: Delivery Models, Disparities and Pandemics" for ATS 2021.

At the conclusion of this project, the co-chairs anticipate an application for an ATS Workshop for ATS 2022 (or similar activity) related to the development of web-based educational and training modules to enhance dissemination of the policy statement and provide foundational primary palliative care training opportunities for ATS clinicians. These modules are expected to be in the form of a virtual classroom or a series of webinars by working group participants summarizing the sessions of the ATS 2021 meeting along with additional training content.

1. Kavalieratos D. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. JAMA. 2016 Nov 22;316(20):2104-2114.
2. Aslakson RA. Developing a Research Agenda for Integrating Palliative Care into Critical Care and Pulmonary Practice To Improve Patient and Family Outcomes. J Palliat Med. 2017 Apr;20(4):329-343.
3. Bruera E. Integrating supportive and palliative care in the trajectory of cancer: establishing goals and models of care. J Clin Oncol. 2010 Sep 1;28(25):4013-7. doi: 10.1200/JCO.2010.29.5618. Epub 2010 Jul 26.
4. Halpin DMG. Palliative care for chronic obstructive pulmonary disease: signs of progress, but still a long way to go. Am J Respir Crit Care Med 2018;198:1356–1358.
5. Kreuter M. Palliative care in interstitial lung disease: living well. Lancet Respir Med. 2017 Dec;5(12):968-980.
6. Ferrell BR, Temel JS, Temin S. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update J Clin Oncol. 2017 Jan;35(1):96-112. doi:

10.1200/JCO.2016.70.1474. Epub 2016 Oct 28.

7. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp.

* B. If you are requesting a face-to-face meeting, please provide a detailed agenda that includes:

- the topic/activity
- the presenter/discussant/group leader name(s),
- start time
- duration (if not clear from the next topic/activity's start time).

Tip. In person meetings are most successful when there is ample time for discussion spread throughout the meeting. It is often helpful to document group/sub-group discussion as a separate topic/activity.

[2021_Meeting_Agenda_Final.docx]

* If you have chosen to develop a Workshop Report as part of this project, please complete a draft agenda below for the workshop. Please click "add new" to add a new agenda item.

* C. PROPOSED PARTICIPANTS - *Every guideline must have a methodologists. Please include in proposed participants. For more details contact ATS Documents Department documents@thoracic.org*

- Include a list of all planned participants. For '**area of expertise relevant to the project**', provide sufficient detail to justify the person's inclusion on this project and to demonstrate their role on the project. For example this could include specific clinical or research expertise and/or prior experience with document development.
- Before commencing work on the project all participants will have their conflict of interest disclosures vetted by the ATS. If the project is co-sponsored by other societies or groups, there may be approvals required before a participant can be formally added to the project committee.

Name : Donald Sullivan
Institution : Oregon Health and Science University
"Role" on Project committee : Co Chair
Area of Experties relevant to project : Thoracic oncology, Behavioral Science, Palliative care, Psychology
Email : sullivad@ohsu.edu
Airfare :
Country : United States

Name : Anand Iyer
Institution : University of Alabama Birmingham
"Role" on Project committee : Co Chair
Area of Experties relevant to project : COPD, Palliative Care
Email : aiyer@uabmc.edu
Airfare :
Country : United States

Name : Lynn Reinke
Institution : Puget Sound VA Hospital
"Role" on Project committee : Co Chair
Area of Experties relevant to project : Nursing, COPD, Thoracic Oncology, Palliative care
Email : lynn.reinke1@va.gov
Airfare :
Country : United States

Name : Natasha Smallwood
Institution : Royal Melbourne Hospital
"Role" on Project committee : Other
Area of Experties relevant to project : Care models, Symptom Management
Email : nsmallwood@unimelb.edu.au
Airfare :
Country : Australia

Name : Patient Representative
Institution : N/A
"Role" on Project committee : Patient Advocate
Area of Experties relevant to project : PAR patient or caregiver
Email : na@patient.edu
Airfare : Domestic
Country : United States

Name : Patient Representative
Institution : N/A
"Role" on Project committee : Patient Advocate
Area of Experties relevant to project : PAR patient or caregiver
Email : na@patient.edu
Airfare : Domestic

Country : United States

Name : J. Randall Curtis
Institution : University of Washington
"Role" on Project committee : Group Leader
Area of Experties relevant to project : Family engagement, Advance care planning, Communication, Palliative care
Email : jrc@u.washington.edu
Airfare :
Country : United States

Name : Katherine Courtright
Institution : UPENN
"Role" on Project committee : Group Leader
Area of Experties relevant to project : COPD, Behavioral Science, Advance care planning
Email : Katherine.Courtright@uphs.upenn.edu
Airfare :
Country : United States

Name : Douglass White
Institution : University of Pittsburgh
"Role" on Project committee : Member
Area of Experties relevant to project : Ethics, Family and caregiver engagement
Email : whitedb@upmc.edu
Airfare :
Country : United States

Name : Gabriel Bosslet
Institution : Indiana University
"Role" on Project committee : Member
Area of Experties relevant to project : Inappropriate care, Training/education, Medical education section
Email : gbosslet@iupui.edu
Airfare :
Country : United States

Name : Kathleen Lindell
Institution : University of Pittsburgh
"Role" on Project committee : Member

Area of Experties relevant to project : Nursing, ILD, Palliative care
Email : lindellko@upmc.edu
Airfare :
Country : United States

Name : Cynda Rushton
Institution : Johns Hopkins University
"Role" on Project committee : Member
Area of Experties relevant to project : Nursing, Ethics, HPNA Representative
Email : crushto1@jhu.edu
Airfare : Domestic
Country : United States

Name : Christiane Hartog
Institution : Christiane Hartog
"Role" on Project committee : Other
Area of Experties relevant to project : Communication, Ethics
Email : Christiane.Hartog@med.uni-jena.de
Airfare : International
Country : Germany

Name : Christopher Cox
Institution : Duke University
"Role" on Project committee : Other
Area of Experties relevant to project : Palliative care, Health policy, Behavioral Science
Email : christopher.cox@duke.edu
Airfare :
Country : United States

Name : Erin Kross
Institution : University of Washington
"Role" on Project committee : Group Leader
Area of Experties relevant to project : Palliative care, Outcomes research, Behavioral science
Email : ekross@u.washington.edu
Airfare :
Country : United States

Name : Kimberly Johnson
Institution : Duke University

"Role" on Project committee : Other

Area of Experties relevant to project : Health disparities, Geriatrics

Email : johns196@mc.duke.edu

Airfare : Domestic

Country : United States

Name : Judith Nelson

Institution : Memorial Sloan Kettering Cancer Center

"Role" on Project committee : Member

Area of Experties relevant to project : Law, Health policy, Palliative care

Email : judith.nelson@mskcc.org

Airfare :

Country : United States

Name : Helen Sorenson

Institution : University of Texas Health Sciences Center

"Role" on Project committee : Other

Area of Experties relevant to project : Respiratory Therapy, Symptom management

Email : sorenson@uthscsa.edu

Airfare :

Country : United States

Name : Mary McPherson

Institution : University of Maryland

"Role" on Project committee : Other

Area of Experties relevant to project : Pharmacy, Symptom management

Email : mmcphers@rx.umaryland.edu

Airfare :

Country : United States

Name : Matthew Maddocks

Institution : Kings College London

"Role" on Project committee : Group Leader

Area of Experties relevant to project : Respiratory Therapy, Care models, COPD

Email : matthew.maddocks@kcl.ac.uk

Airfare : International

Country : United Kingdom

Name : Richard Mularski

Institution : Kaiser Permanente Northwest
"Role" on Project committee : Member
Area of Experties relevant to project : Community practice, COPD, Palliative care, Original Guideline Committee Member
Email : Richard.a.mularski@kpchr.org
Airfare :
Country : United States

Name : Diane Meier
Institution : Icahn School of Medicine of Mount Sinai
"Role" on Project committee : Speaker
Area of Experties relevant to project : CAPC Founder, Geriatrics, Palliative care
Email : diane.meier@mssm.edu
Airfare : Domestic
Country : United States

Name : J. Daryl Thornton
Institution : Case Western Reserve University
"Role" on Project committee : Group Leader
Area of Experties relevant to project : Health disparities, Behavioral science
Email : daryl.thornton@case.edu
Airfare :
Country : United States

Name : Susan Enguídanos
Institution : University of Southern California
"Role" on Project committee : Member
Area of Experties relevant to project : Social work, Geriatrics, Disparities in end-of-life care
Email : enguidan@usc.edu
Airfare : Domestic
Country : United States

Name : Daisy Janssen
Institution : Maastricht University
"Role" on Project committee : Member
Area of Experties relevant to project : Psychology, COPD, Palliative care
Email : daisyjanssen@ciro-horn.nl
Airfare :

Country : Netherlands

Name : Morag Farquhar
Institution : University of Cambridge
"Role" on Project committee : Member
Area of Experties relevant to project : Sociology, Symptom Management , Caregivers
Email : M.Farquhar@uea.ac.uk
Airfare : International
Country : United Kingdom

Name : Robert Fowler
Institution : Sunnybrook Health Sciences Center
"Role" on Project committee : Member
Area of Experties relevant to project : Epidemiology/outcomes research, Quality improvement, Palliative care
Email : rob.fowler@sunnybrook.ca
Airfare :
Country : Canada

* D. The ATS encourages diversity and inclusion on all its committees and projects and has identified several groups that have been historically under-represented on ATS committees. It may not be possible or needed to include all theses groups on this project and there is no expected quota for diversity and inclusion. To facilitate the review of the proposed committee, please complete this summary of diversity and inclusion. Please indicated if your proposed participants include any of the following Underrepresented in Medicine Definition

Diversity : Patient/Family
How Many? : 2
Comments/Clarifications : PAR Representatives

Diversity : Women
How Many? : 16
Comments/Clarifications : Including 1 PAR Representative

Diversity : Underrepresented minorities in medicine
How Many? : 3
Comments/Clarifications : Underrepresented minorities

Diversity : International repersentatives
How Many? : 6

Comments/Clarifications : Canada, Australia, Germany, The Netherlands and United Kingdom

Diversity : Early career representatives
How Many? : 9
Comments/Clarifications : Early Career representatives

Diversity : Non-MD/DO professionals
How Many? : 8
Comments/Clarifications : Nursing, Respiratory Therapy, Sociology, Social Work, and Pharmacy

SECTION IV - TIMELINE

Tentative timetable. Please provide a sufficiently detailed timeline to support that the necessary activities/tasks needed to complete the project will be completed within the expected timeframe (e.g., CPGs submitted for publications within 2 years; all other documents submitted within 1 year). This should include pre- and post meeting work, such as conference calls, in-person meetings, literature review, writing deadlines (outlines, first drafts, review by co-authors etc.). This section should NOT include meeting agendas. Please include a completion date for each task through submission for peer review (for document projects) or completion (for non-document projects)

Activity/Task : Initial steering committee planning meeting
Location/Communication modality : teleconference
# of Participants : 4
Anticipated Started Date (MM/DD/YYYY) : 02/01/2021
Anticipated Completion Date (MM/DD/YYYY) : 02/01/2021

Activity/Task : Secure co-sponsorship from organizations and identify representatives
Location/Communication modality : email
# of Participants : 4
Anticipated Started Date (MM/DD/YYYY) : 02/01/2021
Anticipated Completion Date (MM/DD/YYYY) : 05/01/2021

Activity/Task : Co-chairs develop introductory materials (Aims 2 and 3)
Location/Communication modality : teleconference
# of Participants : 3
Anticipated Started Date (MM/DD/YYYY) : 02/01/2021
Anticipated Completion Date (MM/DD/YYYY) : 03/15/2021

Activity/Task : Distribute introductory material to entire working group
Location/Communication modality : email

# of Participants : 27

Anticipated Started Date (MM/DD/YYYY) : 03/15/2021

Anticipated Completion Date (MM/DD/YYYY) : 03/15/2021

Activity/Task : Steering committee members and breakout group facilitators to review group structure/function and to develop briefing packets for the breakout groups which will consist of relevant scientific articles, group objectives, and suggestions for reporting group findings-Part 1 (Aims 2 and 3)

Location/Communication modality : teleconference

# of Participants : 14

Anticipated Started Date (MM/DD/YYYY) : 03/20/2021

Anticipated Completion Date (MM/DD/YYYY) : 03/20/2021

Activity/Task : Steering committee members and breakout group facilitators to review group structure/function and to develop briefing packets for the breakout groups which will consist of relevant scientific articles, group objectives, and suggestions for reporting group findings-Part 2 (Aims 2 and 3)

Location/Communication modality : teleconference

# of Participants : 14

Anticipated Started Date (MM/DD/YYYY) : 04/20/2021

Anticipated Completion Date (MM/DD/YYYY) : 04/20/2021

Activity/Task : Initial working group meeting (Aims 1, 2 and 3)

Location/Communication modality : ATS 2021 or Virtual

# of Participants : 27

Anticipated Started Date (MM/DD/YYYY) : 05/15/2021

Anticipated Completion Date (MM/DD/YYYY) : 05/21/2021

Activity/Task : Writing committee meeting: solicit feedback from group facilitators and PAR member

Location/Communication modality : teleconference

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 06/01/2021

Anticipated Completion Date (MM/DD/YYYY) : 06/01/2021

Activity/Task : First draft composition (Aim 1)

Location/Communication modality : NA

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 06/02/2021

Anticipated Completion Date (MM/DD/YYYY) : 09/01/2021

Activity/Task : Writing committee meeting/draft discussion

Location/Communication modality : teleconference

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 09/15/2021

Anticipated Completion Date (MM/DD/YYYY) : 09/15/2021

Activity/Task : Meeting of writing committee to review draft and put together working document for distribution

Location/Communication modality : teleconference

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 10/01/2021

Anticipated Completion Date (MM/DD/YYYY) : 10/01/2021

Activity/Task : Evaluation of draft by full working committee

Location/Communication modality : email

# of Participants : 27

Anticipated Started Date (MM/DD/YYYY) : 10/07/2021

Anticipated Completion Date (MM/DD/YYYY) : 10/30/2021

Activity/Task : Conference call- addressing revisions

Location/Communication modality : teleconference

# of Participants : 27

Anticipated Started Date (MM/DD/YYYY) : 11/07/2021

Anticipated Completion Date (MM/DD/YYYY) : 11/07/2021

Activity/Task : Second draft preparation (Aim 1)

Location/Communication modality : NA

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 11/08/2021

Anticipated Completion Date (MM/DD/YYYY) : 12/30/2021

Activity/Task : Conference call- discussion of second draft and further revisions

Location/Communication modality : teleconference

# of Participants : 27

Anticipated Started Date (MM/DD/YYYY) : 01/15/2022

Anticipated Completion Date (MM/DD/YYYY) : 01/15/2022

Activity/Task : Final manuscript preparation (Aim 1)

Location/Communication modality : NA

# of Participants : 10

Anticipated Started Date (MM/DD/YYYY) : 01/16/2022
Anticipated Completion Date (MM/DD/YYYY) : 02/20/2022

Activity/Task : Final working group meeting: final approval of consensus policy statement (Aim1)
Location/Communication modality : teleconference
# of Participants : 27
Anticipated Started Date (MM/DD/YYYY) : 03/01/2022
Anticipated Completion Date (MM/DD/YYYY) : 03/01/2022

Activity/Task : Final manuscript submission (Aim1)
Location/Communication modality : NA
# of Participants : 27
Anticipated Started Date (MM/DD/YYYY) : 03/31/2022
Anticipated Completion Date (MM/DD/YYYY) : 03/31/2022

Activity/Task : Review major themes developed via consensus by working group
Location/Communication modality : email
# of Participants : 27
Anticipated Started Date (MM/DD/YYYY) : 05/22/2021
Anticipated Completion Date (MM/DD/YYYY) : 06/01/2021

SECTION V - BUDGETS

FY2021 PROPOSED ATS BUDGET

* Round Trip Coach Airfare-Domestic ($575 per person) Number of Persons? 6
* Round Trip Coach Airfare-International ($2000 per person) Number of Persons? 3
* Hotel and per diem (Full Day Meeting at ATS Conference Fri & Sat Only) ($425 per person) Number of Persons? 27
* Breakfast Meeting at ATS Conference ($75.00 Per Person) Number of Persons? *-- empty --*
* Lunch Meeting at ATS Conference ($75.00 Per Person) Number of Persons? *-- empty --*

Conference Calls (# of people x # minutes x 0.10)

* # of people 10
* # of minutes 600
* # of calls 10

* Medical Librarian - This item requires approval and justifications from document development staff (up to $5000) *-- empty --*

Other Project Expenses

☑ Not Applicable

SECTION VI - Conflict of Interest Management

ATS members and others participating in official ATS projects have diverse experiences and relationships that positively contribute to project development. Disclosure and consideration of potential "conflicts of interest" (COI) -- relationships and personal interests that could be perceived as unduly influencing a participant's generation or assessment of evidence, and thereby potentially misinforming healthcare decision makers -- is essential to assure that official ATS projects always reflect the best available evidence and scientific rigor. Therefore, for all proposed projects:

- Yes, I agree to follow COI rules

SECTION VII - Chair Acknowledgement

Submission of application constitutes Electronic signature. Electronic Signatures are considered binding.

SECTION VIII - Revising Application After Reviewer Feedback

Please do not complete until Planning Committee reviews are received.

* Revision - Tell us what revisions have been made and how reviews from Planning Committee were addressed

Feedback from the DDIC

1. The proposal is exceptionally well written with a logically designed methodology. It is an ambitious and comprehensive endeavor, but the expertise of the proposed participants and extended timeline makes it achievable. Dr. Sullivan skillfully addressed the rationale and importance of updating the palliative care policy statement. Overall, high impact / ATS relevancy; solid methods; proposal has been highly responsive to prior submission comments/critiques.

2. In addition to Ferrell, Temel and Temin (reference 6, Methodology Section), Dr. Sullivan and co-chairs may also want to consider the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition.

Response: We have added this important guideline that will be distributed to the project participants by March 2021 during the pre-meeting activities.

3. Although a minor issue of inconsistency, thirteen of the proposed participants are identified as group leaders, while the body of the proposal (Working Group Meeting Agenda) describes group facilitators with

one designated lead for the small groups.

Response: On-line project template drop-down menu did not have group facilitator as a "Role" type so we have designated the 6 non-lead, small group facilitators as "Other".

4. Minor typo in the Pre-Meeting section, paragraph 2, 1st sentence, change from March 2020 to March 2021.

Response: Corrected to March 2021

Feedback from BSHSR Planning Committee The committee again felt that this was an outstanding proposal, even stronger than the application submitted last year.

Strengths: - Very high impact and relevance to the ATS. There is a significant need for this statement, as the last ATS statement on palliative care was in 2008. The ATS should lead in providing policy recommendations for palliative care among patients with pulmonary disease. This is an ambitious project, but the co-chairs and participants have tremendous expertise in this area and lend credence to the ability of the project to be successful. Multi-society representation is a real strength. The timeline is achievable. The narrow focus on COPD, ILD, and lung cancer is a strength which helps to make the project more achievable. The co-chair and participants are outstanding, recognized experts in this topic.

Weaknesses:
1. Consider including more Canadian/European participants. Consider including psychologists, social workers as participants.

Response: To make the policy statement more impactful, we have included a more diverse working group including International (Canada, UK and The Netherlands) and working group members with psychology, sociology, and social work expertise.

- Susan Enguídanos, PhD, MPH; University of Southern California; social work, geriatrics, disparities in end-of-life care
- Daisy Janssen, MD; Maastricht University, The Netherlands; psychology, COPD, palliative care
- Morag Farquhar, PhD; University of Cambridge, United Kingdom; sociology, symptom management, caregivers
- Robert Fowler, MD; Sunnybrook Health Sciences Center, Ontario; epidemiology/outcomes research, quality improvement, palliative care

2. *Consider discussing how the COVID-19 pandemic impacts palliative and end-of-life care decision-making.*

Response: We absolutely agree and believe this is a strength of our proposal given its timeliness. In the

original submission, we have highlighted how the COVID pandemic has increased emphasis on advance care planning and timely palliative care (4th paragraph, Section II) describing the goals and objectives of the project. In our original face-to-face meeting agenda (which is difficult to find given the new ATS attachment format), we included a small group (#6) entitled “Lasting lessons in future palliative care planning from the pandemic” that will be led by J. Randall Curtis who has authored several important publications related to palliative care during the pandemic. Additionally, we will incorporate work by Dr. Reinke (co-chair), Co-Director of the Palliative Care Graduate Training Program at the University of WA, who co-created COVID-19 specific communication training modules for inter-professional clinicians, one specifically focusing on critically ill patients in the ICU.

3. More attention should be given to the engagement of patients (and family members/caregivers). Though patient representatives are listed in the proposed participants, it is not clear how and when their specific experiences and expertise will be sought out (and what "type" of patients or surrogates will be invited- e.g., those living with chronic respiratory disease and who have engaged in both primary and specialty palliative care, those who have had loved ones die of chronic respiratory disease).

Response: PAR representatives are an essential component of this project as palliative care is a patient- and family-centered topic. PAR representatives who have or are a family caregiver to a patient with advanced respiratory disease (COPD, ILD, or Lung CA) and have prior experiences with palliative care will be sought. PAR representatives will be engaged in all aspects of the development of the policy statement including as an invited speaker, small group participants, and as an essential part of the writing committee. Co-chairs will engage with and encourage active PAR representative participation throughout pre-meeting, meeting, and post-meeting activities including evaluation of all policy statement drafts. Descriptions of engagement of PAR representatives has been expanded for clarity in the Methodology section.

4. Consider being more explicit about the methods that will be used to finalize group conclusions.

Response: The ATS 2021 meeting will conclude with a summation session where we identify areas of agreement and dissent within our major themes using consensus based methodology (i.e., modified Delphi approach). A modified Delphi approach will allow the co-chairs to generate a comprehensive list of common themes that address our primary aims. Co-chairs will distribute the list to the workshop participants to reach consensus for the key elements of the framework. Each participant will be asked to rate the importance of each item, as well as to suggest potential additional items. Consensus will be considered reached when 80% of the participants strongly agree that an element should be included/excluded. If agreement is not reached in the first round, or where new suggestions are added, then this item will be carried forward to a second round along with an aggregated summary of the first

round results. Participants will again rank the items to reach consensus. A finalized list of common themes, developed by consensus-based methodology, will be distributed via email by the co-chairs to the full working committee for review immediately following the ATS 2021 meeting. We have added: “Review major themes by full working committee developed via consensus” by email to the project timeline.

5. Consider being more explicit about how the timeline maps onto the specific aims.

Response: We have more explicitly mapped how the specific aims relate to Activity/Task(s) in the Timeline section of the application.

* Can we share your application with ATS members if it is deemed a model application by the Program Review Subcommittee (PRS)?

Yes

ATS BUDGET SUMMARY CHART

Line Item	Budget Parameters	Number of Persons	Total
Round Trip Coach Airfare-Domestic *($575 per person)*	*$575.00*	6	$3,450.00
Round Trip Coach Airfare-International *($2000 per person)*	*$2,000.00*	3	$6,000.00
Hotel and per diem (Full Day Meeting at ATS Conference Fri & Sat Only) *($425 per person)*	*$425.00*	27	$11,475.00
Breakfast Meeting at ATS Conference *($75.00 Per Person)*	*$75.00*		N/A
Lunch Meeting at ATS Conference ($75.00 Per Person)	*$75.00*		N/A
Conference Calls *(# of people x # minutes x 0.10)*	*10 x 600 x 0.10* = $600.00	**(# Calls)** 10	$6,000.00
Medical Librarian – This item requires approval and justifications from document development staff *(up to $5000)*	N/A	N/A	N/A
Other Project Expenses – Must provide Budget justification	N/A	N/A	N/A
Note: *Your proposed budget may be adjusted by staff and/or PRS to comply with ATS budgetary Policies and Procedures.*		**Total**	***$26,925.00***