

Physician-Assisted Death: Scanning the Landscape and Potential Approaches— A Workshop

DRAFT AS OF JANUARY 8, 2018

February 12–13, 2018

National Academy of Sciences Building
2101 Constitution Avenue
Washington, DC

WORKSHOP OBJECTIVES

The National Academies of Sciences, Engineering, and Medicine (NASEM) is convening a workshop exploring the question of when and under what circumstances terminally ill patients can access life-ending medications with the aid of a physician. This question has received increasing attention as a matter of public opinion and of public policy, and is being debated by ethicists, clinicians, patients and their families. Inconsistent legal terrain perpetuates questions and challenges around the topic of physician-assisted death (PAD), and this workshop will serve as a neutral space to facilitate dialogue and explore what is currently known about PAD, in order to help inform ongoing discussions between patients, their providers, and other health care stakeholders.

This workshop will include discussions, and background materials, that address:

- **What is known empirically about the access to and practice of physician-assisted death in the U.S. and in other countries?**
- **What are potential approaches for physicians, including those practicing in states where it is legal, those who receive a request for access when the practice is legal in nearby states but not in the state of practice, and those who practice in a state where it is legal but are personally opposed to physician-assisted death.**
- **What is known about how palliative care and hospice services have incorporated the practice of physician-assisted death in states where it is legal?**

DAY 1: February 12

8:30 a.m. Breakfast Available Outside Meeting Room

9:00 a.m. Opening Remarks (20 mins)

Jim Childress, University of Virginia (*Workshop Chair*)

Topics:

- Goals and Scope of the Workshop
- Outline of the Ethical Arguments

SESSION I: WHAT DO WE KNOW? / THE EVIDENCE AND TERMS OF DISCUSSION

Session Objectives:

- Discuss an overview of the evidentiary landscape.
 - What is known about current practice? What are the limitations of current evidence about practices?
 - Is the evidence base adequate to inform ethical debates about the practice? Which ethical arguments about physician-assisted death could be examined and informed by scientific evidence and which cannot?
- Discuss an overview of the regulatory landscape: Where is this legal, what is legal, and what may be on the horizon?
- Highlight terminology, including gaps or ambiguity in key definitions.

Session Chair: Linda Ganzini

9:20 a.m. **Interview – The Landscape from the Perspective of Patients and Their Families**

- **Dan Diaz**, Brittany Maynard's husband; Latino Leadership Council, Compassion and Choices

Interviewed by Anthony Back, Professor of Medicine, University of Washington

9:50 a.m. **Colloquy – Evidentiary Landscape**

- **Linda Ganzini**, Professor of Psychiatry and Medicine, Oregon Health and Sciences University
- **Anthony Back**, Professor of Medicine, University of Washington

10:20 a.m. ***Discussion with workshop participants moderated by Linda Ganzini***

10:30 a.m. **Break**

10:45 a.m. **Definitional Framework**

Legal/Regulatory Landscape (20 mins)

- **David Orentlicher**, Co-Director, UNLV Health Law Program and The Cobeaga Law Firm Professor of Law, University of Nevada, Las Vegas

Key Terms and Taxonomy (30 mins)

- **Scott Kim**, Senior Investigator, Department of Bioethics, NIH Clinical Center
- **Tom Strouse**, Medical Director, Stewart and Lynda Resnick Neuropsychiatric Hospital at UCLA

11:35 a.m. ***Discussion with workshop participants moderated by Linda Ganzini***

12:15 p.m. **LUNCH**

SESSION II: PROVIDER EXPERIENCES & APPROACHES

Session Objectives:

- Outline current provider practices when a request is made. Discuss the experiences and approaches of health care providers across different jurisdictions.
- Outline the statutory safeguard requirements and implications of them – how they are implemented and experienced.
- Discuss potential approaches for different case scenarios: cases that do not fit the applicable legal definitions; cases in jurisdictions where the practice is not legal; and cases in jurisdictions where the practice is legal but has been refused by a provider.

Session Co-Chairs: David Magnus and Neil Wenger

1:00 p.m. **Panel #1: Current Landscape: Implementation and Practice**

Panel Moderator: David Magnus

Presentations:

- **Thaddeus Pope**, Director, Health Law Institute and Professor of Law, Mitchell Hamline School of Law, Minnesota
- **Courtney Campbell**, Hundere Professor in Religion and Culture, Oregon State University School of History, Philosophy, and Religion
- **Frances Norwood**, Assistant Research Professor in Anthropology, George Washington University
- **Helene Starks**, Associate Professor, Department of Bioethics and Humanities, University of Washington School of Medicine
- **Anita Silvers**, Professor and Associate Chair, San Francisco State University Department of Philosophy

Group Discussion

2:45 p.m. **Break**

3:00 p.m. **Panel #2: Potential Approaches for Handling Requests**

Panel Moderator: Neil Wenger

Presentations:

- **Peter Reagan**, family physician, Oregon
- **Erik Fromme**, Director, Serious Illness Care Program, Ariadne Labs, Dana Farber Cancer Institute
- **Mara Buchbinder**, Associate Professor of Social Medicine, UNC Chapel Hill School of Medicine
- **Barbara Koenig**, Professor, Institute for Health and Aging and Department of Anthropology, History, and Social Medicine and Director, UCSF Bioethics, UCSF School of Medicine
- **Timothy Quill**, Professor of Medicine, Psychiatry, Medical Humanities and Nursing, Palliative Care Division, University of Rochester School of Medicine

Group Discussion

4:45 p.m. **Discuss Plan for Day Two**

5:00 p.m. **Adjourn**

DAY 2: February 13

8:30 a.m. Breakfast Available Outside the Meeting Room

9:00 a.m. **Recap Day One and Discussion with Workshop Participants (10 mins)**

Jim Childress, University of Virginia (*Workshop Chair*)

SESSION III: PHYSICIAN-ASSISTED DEATH IN THE BROADER CONTEXT

Session Objectives:

- Discuss what is known about how palliative care and hospice have incorporated the practice of physician-assisted death in states where it is legal.
- Discuss perspectives and practices of long-term care provider systems.

Session Co-Chairs: Joanne Lynn and James Tulsky

9:10 a.m. **Palliative Care and Hospice**

Panel Moderator: James Tulsky

Presentations:

- **Stephanie Harman**, Clinical Associate Professor, Medicine, Stanford University; Medical Director, Palliative Care, Stanford Health Care
- **Gary Pasternak**, Medical Director, *Mission Hospice*
- **Steve Pantilat**, Kates-Burnard and Hellman Distinguished Professor in Palliative, University of California, San Francisco; Director of the UCSF Palliative Care Program

Group Discussion

10:00 a.m. **Long-Term Services and Supports**

Panel Moderator: TBA

Presentations:

- **Joanne Lynn**, Director, Center for Elder Care and Advanced Illness, Altarum
- **Cheryl Phillips**, President and CEO, SNP Alliance

Group Discussion

10:50 a.m. **Break**

SESSION IV: DATA COLLECTION IN THE U.S. AND OTHER COUNTRIES

Session Objective:

- Consider what we can learn from other countries, focusing on how data collected in the U.S. compare with the data collection in other countries with legal aid-in-dying frameworks.

Session Chair: Nancy Berlinger, The Hastings Center

11:00 a.m. **Data Collection in Canada and the Netherlands**

- **Jennifer Gibson**, Director, University of Toronto Joint Centre for Bioethics
- **Bregje Onwuteaka-Philipsen**, Amsterdam Public Health Research Institute

11:40 a.m. **Data Collection in the U.S.**

- **Katrina Hedberg**, Health Officer & State Epidemiologist, Oregon
- **Matthew Wynia**, Director of the Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus

Group Discussion moderated by Nancy Berlinger

12:30 p.m. **Lunch**

SESSION V: OBSERVATIONS FROM THE WORKSHOP AND POTENTIAL NEXT STEPS FOR THE FIELD

Session Objectives:

- Reflect on key takeaways from the panel presentations and discussions.
- Highlight evidentiary gaps that, if filled, would help inform potential approaches for health care providers, and discuss potential approaches to address identified evidentiary gaps.
- Explore what is next in the conversation – including potential related issues that remain undeveloped but linger on the horizon.

Session Chair: Jim Childress

1:15 p.m. **Observations from Session Chairs (10 mins ea)**

Moderator: Scott Halpern, University of Pennsylvania

- **Linda Ganzini**, Session I: What Do We Know? / The Evidence and Terms of Discussion
- **David Magnus and Neil Wenger**, Session II: Provider Experiences and Approaches
- **Joanne Lynn and James Tulsky**, Session III: Physician-Assisted Death in the Broader Context
- **Nancy Berlinger**, Session IV: Data Collection in the U.S. and Other Countries

1:55 p.m. **Reflections on the Evidentiary Gaps and Key Takeaways from the Workshop**

Panel Discussion moderated by Jim Childress

- **James Tulsky**, Chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute
- **Neil Wenger**, Professor of Medicine, Division of General Internal Medicine, and Director, UCLA Healthcare Ethics, UCLA School of Medicine

2:30 p.m. **Discussion with Workshop Attendees and Speakers**

3:00 p.m. **WORKSHOP ADJOURNS**

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