

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

February 12–13, 2018

National Academy of Sciences Building
2101 Constitution Avenue NW, Washington, DC

This National Academies of Sciences, Engineering, and Medicine workshop will explore the evidence base and research gaps relating to the implementation of the clinical practice of allowing terminally ill patients to access life-ending medications with the aid of a physician. The workshop is sponsored by the Greenwall Foundation. The workshop will examine what is known, and unknown, about how physician-assisted death is practiced and accessed in the United States; it will not be a focus of the workshop to discuss at length the moral or ethical arguments for or against the practice of physician-assisted death. The workshop will serve as a neutral space to facilitate dialogue in order to help inform ongoing discussions between patients, their providers, and other health care stakeholders.

Statement of Task

- What is known empirically about the access to and practice of physician-assisted death in the U.S. and in other countries?
 - In states where it is legal:
 - What is known about who accesses it and the impact the practice has on the patient and family experience of death?
 - What is known about whether legal safeguards are observed?
 - What is known about whether concerns about vulnerable populations have been realized when it is practiced?
 - In states where it is not legal:
 - What is known about the current practice of physician-assisted death and what patients are accessing it?
 - Is its practice accompanied by safeguards, if any, and how do such safeguards compare with safeguards enacted in states where it is legalized?
 - What are the gaps in empirical data about the practice of physician-assisted death in the U.S.?
 - How do the data collected in the U.S. compare with the data collection in countries like the Netherlands, which have more extensive reporting and data collection?
- What are potential approaches for physicians:
 - Who practice in a state where it is legal but are personally opposed to physician-assisted death.
 - Who receive a request for access but the situation does not adhere to the applicable state's legal framework.
 - Who receive a request for access when the practice is legal in nearby states but not in the state of practice.
- 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

Lecture Room

OPENING REMARKS

9:00 – 9:10a.m.

Welcome and Introductory Remarks

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

Session I: WHAT DO WE KNOW? THE EVIDENCE AND TERMS OF DISCUSSION 9:10a.m. – 1:00p.m.

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*

9:10 a.m. Interview – A Patients and Family Perspective

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

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

9:30 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
- **Dan Sulmasy**, Andre Hellegers Professor of Biomedical Ethics, Kennedy Institute of Ethics, Departments of Philosophy and Medicine, Georgetown University

10:30 a.m. Discussion with workshop participants moderated by *Linda Ganzini*

10:45 a.m. Break

11:00 a.m. **Legal and Conceptual Frameworks**

Legal/Regulatory Landscape

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

Terminal Illness: Operationalizing the Definition

- **Joanne Lynn**, Director, Center for Elder Care and Advanced Illness, Altarum

Key Terms and Taxonomy

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

Respondent

- **John Keown**, Rose F. Kennedy Professor of Christian Ethics, Kennedy Institute of Ethics, Georgetown University

12:30 p.m. **Discussion with workshop participants moderated by Linda Ganzini**

1:00 p.m. **LUNCH**

Session II: PROVIDER EXPERIENCES AND APPROACHES

1:30 – 5:15p.m.

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**

1:30 p.m. **Panel #1: Current Landscape: Implementation and Practice**

Panel Moderator: **David Magnus**, Stanford University

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
- **John Kelly**, New England Regional Director, Not Dead Yet; Director, Second Thoughts

2:45 p.m. ***Discussion with workshop participants moderated by David Magnus***

3:15 p.m. **Break**

3:30 p.m. **Panel #2: Potential Approaches for Handling Requests**

Panel Moderator: Neil Wenger, University of California, Los Angeles

Presentations:

- **Peter Reagan**, family physician, Oregon
- **Erik Fromme**, Director, Serious Illness Care Program, Ariadne Labs, Dana Farber Cancer Institute
- **Timothy Quill**, Professor of Medicine, Psychiatry, Medical Humanities and Nursing, Palliative Care Division, University of Rochester School of Medicine
- **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

4:30 p.m. ***Discussion with workshop participants moderated by Neil Wenger***

5:00 p.m. **Adjourn Day 1**

DAY 2: February 13

NAS Room 125

OPENING REMARKS

9:00 – 9:10a.m.

Recap Day One and Discussion with Workshop Participants

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

Session III: PHYSICIAN-ASSISTED DEATH IN THE BROADER CONTEXT

9:10 – 10:50a.m.

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: James Tulsky, Richard Payne, and Joanne Lynn

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

Panel Moderator: James Tulsky, Dana-Farber Cancer Institute

Presentations:

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

9:50 a.m. **Discussion with workshop participants moderated by James Tulsky**

10:05 a.m. **Long-Term Services and Supports**

Panel Moderator: Richard Payne, Duke University

Presentations:

- **Joanne Lynn**, Director, Center for Elder Care and Advanced Illness, Altarum
- **Cheryl Phillips**, President and CEO, SNP Alliance
- **Barb Hansen**, CEO, Oregon Hospice and Palliative Care Association

10:35 a.m. **Discussion with workshop participants moderated by Richard Payne**

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

Session IV: DATA COLLECTION IN THE U.S. AND OTHER COUNTRIES**11:00a.m. – 12:30p.m.****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 the U.S. and Other Countries**

- ***Katrina Hedberg***, Health Officer & State Epidemiologist, Oregon
- ***Bregje Onwuteaka-Philipsen***, Amsterdam Public Health Research Institute
- ***Jennifer Gibson***, Director, University of Toronto Joint Centre for Bioethics
- ***Matthew Wynia***, Director of the Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus

11:50 a.m. Discussion with workshop participants moderated by *Nancy Berlinger***12:15 p.m. LUNCH****Session V: OBSERVATIONS FROM THE WORKSHOP AND POTENTIAL NEXT STEPS FOR THE FIELD****1:15 – 3:00p.m.****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***1:00 p.m. Observations from the Workshop*****Panel Moderator: Scott Halpern***, University of Pennsylvania

- ***Omega Silva***, Professor Emeritus of Medicine, George Washington University
- ***Daniel Callahan***, Co-founder, President Emeritus, The Hastings Center

1:30 p.m. Discussion with workshop participants moderated by *Scott Halpern***1:45 p.m. Reflections on the Evidentiary Gaps and Key Takeaways from the Workshop*****Panel Moderator: Jim Childress***

- ***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, Richard Payne, 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

2:30 p.m. ***Discussion with workshop participants moderated by Jim Childress***

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