### End of Life Grantmaking in the United States: Summary Report

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Prepared for the John and Wauna Harman Foundation

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### INTRODUCTION

As baby boomers age and policy reform subjects the healthcare system to fresh scrutiny, end-of-life care has in the past few years exploded into the public consciousness. From Atul Gawande's 2014 bestseller *Being Mortal* to regular *New York Times* editorials that explore policy, practice, and belief around death, frank discussions of mortality—once taboo—are gradually entering mainstream discourse. Americans are coming to terms with the expensive, ineffective, and uncoordinated treatment models that so often shape the twenty-first-century experience of dying.

In July, Medicare announced a plan to reimburse healthcare providers for discussions on end-of-life options—a move that promotes those discussions but also raises questions about how and when they should occur and which doctors should be responsible for conducting them. This is typical of the end-of-life field (which many would say only coalesced in the 1980s): each development ushers stakeholders into uncharted territory, demanding that they weigh new questions and confront new challenges.

In 2014, Sherry Consulting was commissioned to perform a field scan examining the landscape of United States foundation funding around end-of-life issues. Since the field is large and growing, and since it encompasses a very broad range of initiatives (from reforming policy to evaluating clinical protocols to renovating hospice facilities), we narrowed our focus to look primarily at work involving media and public engagement.

Over several months, and through a combination of interviews, literature review, and online research, we surveyed the broader history of funding in the space and assembled a series of profiles highlighting select key players (both funders and organizations) currently active; funders who had exited the field but whose earlier contributions were formative; and seminal documents and reports.

In 2015, the funders who commissioned this scan elected to make public an abbreviated and updated version, for the benefit of grantmakers like themselves who wish to become involved in end-of-life work. The new report consists of a short summary outlining the historical and recent context for end-of-life grantmaking, followed by a literature review profiling current funders, select nonprofits and organizations working in the communications field, affinity groups, historical funders, and key literature around end-of-life issues. While the scan is far from exhaustive, it includes many of today's prominent players in this arena, as well as a few emerging actors, and we hope it will facilitate collaboration among new and established grantmakers alike. As momentum around these issues grows, we hope our scan will encourage grantmakers to embark on the journey toward better and more humane end-of-life care, and that it will provide some guidance as they move forward.

We begin with a summary of our scan, first reviewing the history and context of end-of-life grantmaking in the US; then considering more recent developments, including the emergence of new funders; and finally offering a few observations of our own that may be of interest to newer funders.



### **OVERVIEW**

### Historical Philanthropic Investment in the Field

Our review of literature on end-of-life care in the United States positions the 1980s and 1990s as decades that sparked new interest in the issue, inspiring funders and researchers of myriad disciplines to grapple with the healthcare system's deficiencies in caring for the dying. By the end of the 1980s, it was clear to many that critically ill patients suffered unnecessary pain and lacked meaningful clinical and emotional support, and that a national—and even personal—conversation around death was missing. Doctors were unprepared to deal with the death of their patients, patients' end-of-life care wishes weren't being met, and families were left disempowered and unsupported. In addition, the field saw important legal developments:

There also was a fractious and widespread debate about end-of-life care in the news and in related policy and practice circles across the nation. In the early 1990s, the nation was immersed in a struggle about care at the end of life. New laws and high-profile court cases were making headlines. The 1990 Cruzan decision broke new ground by authorizing patients to reject medical treatment, including food and water. Jack Kevorkian, or "Dr. Death" as he was known, came to public attention with his first acknowledged assisted suicide. The Patient Self-Determination Act came into law and required hospitals to inform patients of their right to make treatment choices regarding resuscitation and other life-saving technology. In 1994 Oregon residents voted to approve the "Death with Dignity Act" to legalize euthanasia.<sup>1</sup>

The Robert Wood Johnson Foundation (RWJF) became the first grant-making entity that took determined steps to gather knowledge and support for reforming end-of-life care. Their story in this field begins with the "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments" (SUPPORT). A steppingstone in our understanding of end-of-life care, the study is worth describing in some depth due to its surprising results and its ramifications for the field.

<sup>&</sup>lt;sup>1</sup> "Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field". 2011. Robert Wood Johnson Foundation. Page 7. http://www.rwjf.org/content/dam/farm/reports/reports/2011/rwjf69582



### The SUPPORT Study: Foundation for a Field

"Foundation giving has often helped create academic and public interest in a topic. ... But the sharp increase in research on death demonstrates the growing power of philanthropy almost to create an academic field."<sup>2</sup>

The New Jersey-based Robert Wood Johnson Foundation (RWJF) is the nation's largest foundation working solely on public health issues.<sup>3</sup> Its importance is unparalleled: its end-of-life grantmaking, which ended in 2006, is widely perceived to have built the field of end-of-life care. The RWJF-funded SUPPORT study, which ran from 1988 to 1994, is still considered seminal 20 years after its publication.

SUPPORT sought to "improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying." It involved two phases, and a total of 9,105 adults. Phase I consisted of a two-year prospective observational study, and Phase II a two-year controlled clinical trial with patients and their doctors grouped randomly into an intervention group (n=2,652) and a control group (n=2,152) across five teaching hospitals throughout the US.

Predictably, the Phase I observation period revealed that clinicians did not often follow patient preferences, highlighting "shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death." What happened next was more surprising. Staff expected that Phase II would validate what was then considered the most promising method for improving patient outcomes and care: enhancing patient-physician communication and providing forecasts of treatment outcomes (1501). To that end, the intervention group (physicians and patients) received various forms of supplemental information and support. Physicians were given estimates of the likelihood of survival for various treatments, and specially-trained nurses spoke with patients, families, physicians, and hospital staff to gather preferences, increase understanding of outcomes, attend to pain control, enable advance care planning, and facilitate communication between patients and physicians. (1591)

<sup>&</sup>lt;sup>2</sup> Miller J. "When Foundations Chime In, the Issue of Dying Comes to Life." New York Times, Nov. 22, 1997.

<sup>&</sup>lt;sup>3</sup> See page 19 of literature and organization review

<sup>&</sup>lt;sup>4</sup> Connors, Alfred F., et al. "A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT)." *Jama* 274.20 (1995): 1591

<sup>&</sup>lt;sup>5</sup> "Only 47% of physicians knew when their patients preferred to avoid CPR; 46% of do-not-resuscitate (DNR) orders were written within 2 days of death; 38% of patients who died spent at least 10 days in an intensive care unit (ICU); and for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time." (1591)

The results were discouraging: the intervention group showed no improvement in any of the five targeted outcomes, which were:

- 1. physician understanding of patient preferences;
- 2. incidence and time of documentation of do-not-resuscitate (DNR) orders;
- 3. pain;
- 4. time spent in an intensive care unit (ICU), comatose, or receiving mechanical ventilation before death;
- 5. and hospital resource use. (1592)

The results cast serious doubt on prevailing assumptions about end-of-life care: there were no demonstrable improvements in patient care or outcomes even after significant interventions.

Unexpected and dissatisfying, the conclusion of the SUPPORT study was that merely bolstering patient-physician communication did not improve end-of-life decision-making and care. (1591) The authors cited a need for much more proactive, forceful, and creative efforts to shape end-of-life treatment, but they offered no specific examples or recommendations of what such efforts might entail.

Instead of ignoring or downplaying the study's results, RWJF made them widely available, even launching a communications campaign to disseminate the findings to the public. The staff at RWJF, having spent over \$20 million on the SUPPORT study, entered what they described as two years of collective head-scratching as they looked for ways to move forward.<sup>6</sup> As RWJF worked with numerous experts in the field to guide their course during those two years, another important effort was underway.

### The Institute of Medicine (National Academy of Medicine), and "Approaching Death"

After SUPPORT, the Institute of Medicine (now the National Academy of Medicine) continued to study end-of-life care in an effort to formulate specific recommendations to the field. Partly funded by RWJF, the extensive report "Approaching Death: Improving Care at the End of Life" engaged a committee of experts to define what comprised a "decent or good" and "bad" death, and to make a series of recommendations to strengthen (or create) palliative and hospice care and encourage public conversations about dying.

The committee identified several deficiencies in care for the dying that prevented access to a "decent or good" death: too many people were suffering needlessly at the end of life from errors of omission or commission; systems in place obstructed excellent care; clinical education and training failed to properly prepare healthcare professionals

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<sup>&</sup>lt;sup>6</sup> Improving Care at the End of Life, 8.

to care for the dying; there was too little research on the later stages of disease and palliative care; and, more generally,

"people in this country have not yet discovered how to talk realistically but comfortably about the end of life, nor have they learned how to value the period of dying as it is now experienced by most people."<sup>7</sup>

The committee offered "Recommendations and Future Directions" to guide policymakers, organizations, physicians and patients towards more compassionate, informed, and effective end-of-life care. The recommendations, directly from the report, were:

- 1. People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care.<sup>8</sup>
- 2. Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.<sup>9</sup>
- 3. Because many problems in care stem from system problems, policymakers, consumer groups, and purchasers of health care should work with health care practitioners, organizations, and researchers to:
  - a. strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;
  - b. develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;
  - c. revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and
  - d. reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering. <sup>10</sup>
- 4. Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients.<sup>11</sup>
- 5. Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.<sup>12</sup>
- 6. The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.<sup>13</sup>

<sup>9</sup> Ibid, 8

<sup>&</sup>lt;sup>7</sup> Field, Marilyn J., and Christine K. Cassel, eds. *Approaching Death: Improving Care at the End of Life*. National Academies Press, 1997. Pages 5-7.

<sup>8</sup> Ibid, 7

<sup>&</sup>lt;sup>10</sup> Ibid, 8

<sup>&</sup>lt;sup>11</sup> Ibid, 10

<sup>&</sup>lt;sup>12</sup> Ibid, 12

<sup>13</sup> Ibid, 12

7. A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.<sup>14</sup>

The report's recommendations informed players across the field, including RWJF at the end of its reconnaissance period. According to a Foundation report, RWJF selected "three main objectives that addressed many elements in the report:

- 1. To improve the knowledge and capacity of health care professionals and others to care for the dying
- 2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying
- 3. To engage the public and professions in efforts to improve end-of-life care."15

Approaching Death: Improving Care at the End of Life "became the touchstone for much of the work later supported by the Foundation. The study came to frame the clinical and related system issues for the field, and laid the footprint for a more evolved field." The report also influenced another major funder, the Open Society Foundations (OSF)—then known as the Open Society Institute—in its "Project on Dying in America," launched in 1994 and detailed below.

### Early Funders: Strengthening Palliative Care

Strengthening palliative care became a funding priority in the emerging field of end-of-life care. By the time *Approaching Death* was released, several other foundations had entered the field. The Open Society Foundation, a private foundation based in New York City and founded by investor and philanthropist George Soros, had established the "Project on Dying in America" (PDIA) at around the time the SUPPORT results came out; between 1994 and 2002, PDIA distributed \$45 million to end-of-life care initiatives. From its outset, PDIA fostered cooperation and collaboration among professionals across a variety of medical, political, and philanthropic fields; in 1995, PDIA, along with RWJF, the Nathan Cummings Foundation, the Rockefeller Family Office, and the Commonwealth Fund, formed Grantmakers Concerned with Care at the End of Life (an affinity group that is no longer active).

These and other foundations recognized that faculty members and clinicians would spearhead meaningful changes around end-of-life care. They also noted a lack of institutionalized channels for the creation of palliative care knowledge, training,

<sup>15</sup> RWJF, 2003

<sup>16</sup> Improving Care at the End of Life, 10

<sup>14</sup> Ibid, 12

<sup>&</sup>lt;sup>17</sup> See page 22 of literature and organization review

certifications, and standards. The work required would be, at its essence, a medical education reform initiative; hence, there was a need to create what RWJF termed a "knowledge field." The Foundation identified the elements of a knowledge field as:

- "Shared identity and sense of mission among the members
- Leaders
- Systems for training education
- Credentialing
- Locations to practice
- Knowledge base
- Quality standards
- Public policy support and funding" 18

Building the end-of-life care field, then, began with a push to make palliative care a legitimate, well-resourced, and sought-after specialty within medicine. This ambitious goal entailed demonstration projects at medical centers around the country, textbook writing, engaging and funding emerging leaders in palliative care, and eventually training and certifying thousands of doctors and nurses in the best practices of caring for the terminally ill.

### An Overview of the Current Funding Landscape

Together, the Robert Wood Johnson Foundation and OSF's "Project on Dying in America" invested over \$200 million to improve end-of-life care between the late 1980's and 2006, when RWJF ended its grant-making in this area (OSF had stopped its funding in 2002). Since then, the funding landscape has shifted somewhat: as the field gained momentum, many new players emerged, but no leading national funder has replaced RWJF and OSF. Nor is there an effective forum for funder collaboration (though efforts to create an active network are underway and may come to fruition as early as this year). Instead, today's landscape of end-of-life funders is a populous and diverse one, with many local and regional grantmakers supporting advocacy efforts, pilot programs, convenings, and research around various aspects of end-of-life care.

A number of funders, including the Cambia Health Foundation, the John A. Hartford Foundation, and the California HealthCare Foundation, have worked extensively to improve training, protocols, and resources around existing or emerging palliative care facilities. A major concern among players focused on palliative care is the disconnect between the clinical training doctors of various specializations receive and the demands they face to lead clear and useful bedside conversations about care—an essential skill many training programs ignore. Dr. Steve Pantilat of UCSF, who heads the Palliative Care Quality Network, has emphasized the need both to expand palliative care programs (particularly at smaller rural hospitals) and to hone training strategies such

<sup>&</sup>lt;sup>18</sup> Improving Care at the End of Life, 11

that teams are better equipped to hold productive conversations with terminal patients and to navigate the nuances of end-of-life choices (for example, they should understand that a cancer patient who refuses chemotherapy may still desire other treatments to ease pain). Other organizations, such as the Coalition for Compassionate Care of California, have supplemented this palliative-care focus by identifying and addressing more specific gaps like the need for training with a multicultural perspective, or for resources aimed at patients with limited fluency in English.

While bolstering palliative care is a top priority for most players in the space, a number of funders have directed their resources toward community outreach and media strategies, educating the general public about end-of-life issues and working to encourage conversations around these issues at the family, community, and national levels. Innovative efforts have studied the way end-of-life choices are addressed in various non-clinical contexts, including popular entertainment; and intriguing pilot projects have tested the potential of different media channels, from videos to interactive websites, to help patients navigate end-of-life options, share their experiences, and document their wishes. Funders like the Archstone Foundation have also examined the role of non-medical actors—specifically spiritual counselors—in end-of-life care.

As Amy Berman, who has explored the field deeply via both her work with the Hartford Foundation and her personal experience with breast cancer, observed in an interview, it can be useful to look at end-of-life funders and organizations on a continuum. At one extreme are projects that seek generally to spur open dialogue on end-of-life issues (for example, the Conversation Project, which guides families through discussions about quality of life and final wishes). At the other end are players more concerned with hospital and hospice settings, who focus specifically on encouraging patients to document their end-of-life wishes (e.g. Physician Orders for Life Sustaining Treatment, or POLST, an initiative dedicated to recording and honoring terminal patients' wishes). Improved end-of-life care in America will require continued and concerted efforts on both ends of this spectrum: at an individual level, patients and physicians should be coached to establish clear, well-documented end-of-life directives; at a community and national level, the public should understand the complexities of end-of-life issues and feel comfortable grappling with them even before they become immediately and personally relevant.

As we move toward more sophisticated and appropriate practices around end-of-life care, experts have pointed to an alarming dearth of next-generation leaders in the field. Many funders have sought to engage this demographic by supporting competitions and "startups" in the space—for example, the California HealthCare Foundation challenged students to build projects stimulating conversation around end-of-life issues, which resulted in projects like the card game My Gift of Grace (now used in hospitals, hospices, and homes around the world). We hope that the recent focus on end-of-life issues in the media and public discourse will inspire younger physicians, researchers, designers, and community leaders to join forces with the many established actors engaged in this sensitive and complex issue.

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### **Promoting Conversation**

In addition to enhancing infrastructure and practices around palliative medicine, some foundation work has sought to engage communities in difficult conversations and reflections around death and end-of-life experiences. But significant work remains to be done on this front: as recent research shows, many dying Americans fail to receive the care they want, either because patient wishes are dismissed or because they do not make their desires clear to doctors and loved ones. This creates unnecessary suffering for patients and their families, as well as costs that strain an already burdened healthcare system.

Such recent research includes the work of the Dartmouth Atlas Project, a healthcare research initiative based at the Dartmouth Institute for Health Policy and Clinical Practice. The Atlas Project has studied end-of-life care as one of its "Key Issues" in a series of reports, significant for two main reasons. First, the research corroborates foundations' claims that palliative and hospice care are better-established and more widely used today than they were in the past. Second, and most informative for future strategy in the field, reports have found that while some patients make use of palliative and hospice care, many receive end-of-life care that is more aggressive than they would have liked, a result of the availability of such care. This suggests that incentives are required move medical practice in the right direction, and that patients and families should continue to be empowered to have their desires for end-of-life care honored.

Similarly, the California HealthCare Foundation (CHCF) released a study in 2013 that is consistent with the Atlas Project's results, albeit focusing specifically on Californians. The CHCF report also highlights a problem at the core of our interest in this field scan: although a majority of those surveyed consistently say it is important to communicate and write out their preferences for end-of-life care, very few actually do so.

The John and Wauna Harman Foundation, a Utah-based grantmaker founded in 1999, works specifically to address end-of-life issues in the realm of communication and public engagement. Its partners have included The Conversation Project, the Wake Up to Dying Project, and PREPARE for Your Care; the Foundation also supported the development of the FRONTLINE documentary *Being Mortal*. The Foundation has partnered with the California HealthCare Foundation to promote community screenings of *Being Mortal* throughout California and to assess its impact as a catalyst for change.

#### New Entrants to the Field

Over the past few years, a number of foundations—new and established—have begun exploring end-of-life issues in their grantmaking. Three notable new players are the Stupski Foundation, the Gordon and Betty Moore Foundation, and the Pew Charitable Trusts.

- **Stupski**, a San Francisco-based foundation formerly devoted to education reform, recently shifted its focus to hunger, poor and minority youth, and end-of-life care, primarily in California and Hawaii, and launched a decade-long \$300-million spend-down. The Foundation is still developing its strategy, but has expressed interest in public engagement and collaboration with other funders.
- Launched by Intel co-founder Gordon and his wife Betty, and also based in the Bay Area, the **Moore Foundation** has a "Patient Care" program that focuses on improving the experience and outcomes of patient care. They are developing their strategy and have expressed interest in identifying and advancing critical building blocks that create a foundation for improving end-of-life care.
- Established in 1948 by the family that founded Sun Oil, **Pew** has a sizeable and diverse portfolio including public opinion research; arts and culture; and environmental, health, state, and consumer policy initiatives. Pew launched its Improving End-of-Life Care project in December 2014. The project seeks to expand access to advance care planning; develop tools to measure the quality of care; highlight innovative ways of providing care to seriously ill people and their families; and improve documentation of patients' wishes for their care near the end of life. Pew's main approach for achieving these goals is federal policy change.

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### **OBSERVATIONS AND FINDINGS**

End-of-life grantmaking is a diverse and dynamic field, difficult to characterize fully and succinctly. The following observations, derived from conversations with funders as well as experts in the field, emerged as particularly salient while we researched the scan; we hope they prove useful to funders navigating this ever-evolving landscape.

- As the end-of-life field continues to grow, funding opportunities abound at all levels. Our research and interviews were met with great enthusiasm from funders and professionals; particularly since the departure of seminal actors like RWJF and OSF from the field, there is a great sense that funder collaborations can leverage impact and spur progress.
- The need for frequent and frank conversation around end-of-life issues is felt pervasively in this field. At a more granular level, these conversations occupy a continuum. On one end are kitchen-table discussions of mortality and care (advocated by initiatives like the Conversation Project); on the other are clearly communicated, legally recorded, and consistently honored medical directives regarding end-of-life treatment (addressed through projects like POLST). Progress in the field will require work on both sides of this continuum, and also—crucially—in the middle, where documenting advance care planning wishes needs to become convenient and customary even for individuals not yet ill enough for POLST. As these efforts progress, we must ensure that increased attention to mortality is accompanied by tangible decision-making tools, enabling people to formalize their end-of-life wishes.
- The healthcare system continues to lack adequate palliative care facilities, resources, and providers for our country's aging population. Moreover, clinicians need to be trained and encouraged to conduct clear, early, and frequent bedside conversations regarding goals of care and end-of-life wishes with patients and their families. Once these wishes have been expressed, doctors and medical systems need to ensure that they are recorded and honored. Progress in this realm will involve updating curricula for medical and nursing students.
- Most end-of-life work targets affluent, educated, and predominantly white
  patient populations; there is substantial need for initiatives addressing (for
  example) culturally diverse populations, disabled patients, and patients for
  whom English is a second language.
- Recent policy developments, notably the Affordable Care Act, promise to fundamentally change medical protocols and incentive structures around endof-life care; however, the full ramifications and opportunities afforded by the Affordable Care Act remain to be seen, and analyzing them is beyond the scope of this report.
- A strong cultural aversion to talking about death makes grappling with end-oflife issues a special challenge. The shift toward accepting and discussing

mortality will have to occur on a societal scale; meanwhile, though, medical decisions are deeply individual. Progress in this field will require work at all levels, from national policy reform to grassroots community organizing.

### **Recent Developments and Next Steps**

As with any funding field, developments in the end-of-life space are ongoing. Since we completed our initial scan, three new resources—a book, a documentary, and a scholarly report—have contributed substantially to the discussion around end-of-life issues. These are Atul Gawande's acclaimed book *Being Mortal*; a FRONTLINE documentary based on Gawande's book; and a comprehensive report from the Institute of Medicine (now the National Academy of Medicine) titled "Dying in America." We summarize each below.

- Released in October 2014, the surgeon and writer Atul Gawande's book *Being Mortal* has helped stir popular interest in end-of-life care and choices. Drawing on anecdotes from his medical career, Gawande exposes a desperate need for improved geriatric care—not necessarily to prolong aging patients' lives, but to dramatically increase their quality. He delves into the role of (and problems with) nursing homes and assisted living facilities, and explores strategies for allowing elderly patients some privacy and autonomy within settings like these. Writing that "the battle of being mortal is the battle to maintain the integrity of one's life to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be," Gawande argues that early and frank conversations about the end of life are essential in freeing patients, families, and clinicians from modern medicine's uncompromising bias toward life-prolonging treatments—treatments that, as the end draws inevitably near, often wind up damaging the "integrity" of a patient's life and death.
- Tom Jennings' and Atul Gawande's new **FRONTLINE documentary**, also called *Being Mortal*, which aired in February 2015, puts to film Gawande's acclaimed book. The hour-long film follows end-of-life patients and their doctors at two separate hospitals, exploring how clinicians can improve their approach to terminal cases and how difficult it can be for non-palliative care doctors to speak honestly with their patients about the process of dying. Jennings hopes the film will spur doctors, families, and communities to reflect on and discuss preparing for the reality of death. The John and Wauna Harman Foundation (profiled below) helped fund this project.
- Following up on its landmark "Approaching Death" report, the Institute of
  Medicine (now the National Academy of Medicine) has released a new study
  titled "Dying in America: Improving Quality and Honoring Individual
  Preferences Near the End of Life." The report draws on literature, expert
  commentary, and public feedback to review key elements of end-of-life care in
  the US, highlighting important conclusions and recommendations:

- Many patients nearing the end of life are often visiting multiple specialists when they could be seeing a single palliative or hospice care physician; this fragmented care must be addressed for the sake of the patients.
- Many of these same patients cannot face and make decisions on their own in a weakened state, and their current doctors may not know them already. If patients use advanced care planning, they can be assured that their doctors will be aware of their end-of-life treatment preferences.
- Doctors ought not to be hesitant to send patients who are not already hospitalized to palliative care as its benefits can help even those not in dire need.
- Since palliative care is found to be far superior to other forms of treatment for end of life patients, training around palliative care in medical and nursing school curricula should be restructured.
- Certain policy issues surrounding Medicare, such as the fee-forservice program, incentivizes the use of additional services that the patient may not always need.

Finally, the report calls for public engagement and education on end of life issues, as well as a need to de-stigmatize the conversations around death and dying that are so essential to one's wellbeing. A more detailed summary of the report can be found in our Literature Review.

These represent just a few recent contributions to the end-of-life discourse; developments in the space are ongoing and ubiquitous, with new resources and commentary emerging almost daily. During the months we spent revisiting and updating our scan, *The New York Times*'s new opinion column "The End" (which grapples with medical, philosophical, legal, and religious aspects of death) featured excellent essays by (among others) a surgeon, a novelist, and a medical researcher; news outlets like *The Atlantic* and *NPR* ran thoughtful coverage of Medicare's new policies around end-of-life discussions; and the *2015 State-by-State Report Card*, a comprehensive survey of access to palliative care across the country, was published by the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC). We hope our scan will serve as a starting point for donors looking to enter this dynamic field and engage with others who share their concern about the problem of dying in America.