Five Big Ideas to Confront Our Nation’s Opioid Crisis
“The Aspen Health Strategy Group, with its bipartisan and multi-sector membership, has developed these ideas to address the opioid crisis in America. It has never been more important for all parties to come together, examine the evidence, and make strides against this deadly problem.”

– THE ASPEN HEALTH STRATEGY GROUP
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Introduction
The U.S. Centers for Disease Control and Prevention (CDC) reports that 33,000 people died from opioid overdoses in 2015. About half of those were due to prescription opioids, with the rest due to heroin and synthetic opioids, such as fentanyl. These deaths were an avoidable and unnecessary tragedy. Early CDC estimates for 2016 tally more than 64,000 overdose deaths from all drugs, a 21% increase from 2015. An estimated two million Americans are abusing prescription pain relievers and an additional 591,000 are addicted to heroin. The growing use and misuse of opioids is a national crisis.

The Aspen Health Strategy Group selected the opioid crisis as its topic for discussion in 2017, its second year. This group of leaders in and outside health care spent three days considering the topic with the assistance of subject matter experts who prepared four background papers to frame the conversation. The group emerged with five big ideas to confront the opioid crisis.

The Aspen Health Strategy Group’s goal is to promote improvements in policy and practice by providing leadership on important and complex health issues. Co-chaired by Kathleen Sebelius and Tommy Thompson, both former governors and former U.S. Secretaries of Health and Human Services, the group is composed of 24 senior leaders across sectors including health, business, media, and technology. More information about the Aspen Health Strategy Group can be found on the Aspen Institute website. This report captures the deliberations of the group, but no specific proposal or statement in the report should be considered to represent the opinion of any individual member of the group.

Background
Harold Pincus and Carlos Blanco trace the growing problem of opioid abuse and its consequences in “The Opioid Crisis in America: An Overview.” They describe the multiple narratives that have been suggested as propelling the growth in opioid use, including a steady increase in the rate of opioid prescriptions and a decrease in the price of heroin and synthetic opioids.
Opioid prescriptions grew following the movement toward increased pain treatment in the 1990s intended to help the many patients who had unrelieved pain. Approximately one-third of U.S. adults are estimated to suffer from chronic pain. While there is strong evidence for the efficacy of opioids for acute pain, they have not been systematically studied for treatment of chronic pain, and there is substantial evidence that they can be harmful when used long-term. Despite this, clinicians routinely prescribe opioids for chronic pain and, at least until recent years, were often cavalier regarding the duration of the prescriptions they wrote for opioids. It is estimated that more than 15 billion opioid tablets were dispensed per year in retail pharmacies in the U.S. in 2013 and 2014, far more per capita than in any other nation. From 1991 to 2013, the prevalence of non-medical use of prescription opioids nearly tripled, from 1.5% to 4.1% of the population, and the prevalence of addiction to prescription opioids tripled, from 0.3% to 0.9% of the population.

Increased accessibility and purity of heroin coupled with reduced price appear to be major drivers of the recent increases in rates of heroin use. Between 2001-2002 and 2012-2013, the prevalence of lifetime heroin use and lifetime heroin addiction (i.e. use or addiction at least once in the person’s lifetime) in the U.S. both increased dramatically. Lifetime heroin use increased from 0.33% to 1.6% and the lifetime prevalence of heroin addiction increased from 0.21% to 0.69%. While there is certainly a relationship between legal opioid prescribing and use of illegal opioids, Pincus and Blanco point out that “the available data suggest
that nonmedical prescription-opioid use is neither necessary nor sufficient for the initiation of heroin use and that other factors are contributing to the increase in the rate of heroin use and related mortality."

The public health consequences of the crisis are staggering. Overdose deaths nearly quadrupled between 2000 and 2014 and most of these overdoses were accidental. Increased risk of HIV and hepatitis C infection are also consequences of opioid addiction; approximately 6% of new HIV diagnoses are due to injectable drug use. The crisis places a tremendous burden on the children, other family members, friends, neighbors and workplace colleagues of people with opioid use disorder.

“Spending for substance use disorder (SUD) treatment in the United States has increased dramatically in recent years and can be expected to continue its rapid expansion,” note Richard Frank and Carrie Fry in “Financing Care for Opioid Use Disorders.” From 2004 to 2014, spending on treatment for substance use disorders grew from $15.3 billion in 2004 to $44.9 billion in 2014, faster than the rate of national health expenditures over the same period.

Payment arrangements for substance use disorder treatment have shifted from primarily grant-based funding of specialty substance use disorder providers to one that relies more heavily on insurance and more closely resembles other elements of the modern U.S. health care system. The prior system of financing relied mostly upon fixed-budget funding of state agencies that directly paid service providers through grants. The role of insurance-based financing, including private insurance, Medicare and Medicaid has expanded.

Two pieces of legislation have significantly altered the financing landscape for opioid use disorder and other substance use disorders. The Mental Health Parity and Addiction Equity Act (MHPAEA), sponsored by U.S. Senators Paul Wellstone and Pete Domenici, requires group health insurance plans that provide mental health and substance use disorder benefits to offer them at parity with medical and surgical benefits. The Affordable Care Act (ACA) extends the reach of the MHPAEA beyond employer-sponsored insurance. The ACA defines mental health and substance use disorder treatments as essential health benefits and extends MHPAEA’s provisions to all plans in the individual and small group markets as well as to those newly eligible for Medicaid. The net effect of these changes is to increase substance use disorder coverage for over 170 million Americans.

Data from the National Household Survey on Drug Use and Health for 2015 indicate that 34% of people with opioid use disorder were covered by Medicaid and 42% by private insurance. Coverage of services does not always lead people
to access them. In 2015, only one-quarter of individuals with opioid use disorder received treatment in the prior 12 months, with the two most likely stated reasons being inability to afford treatment and a lack of readiness to seek treatment.

In combination, the requirements of MHPAEA and the ACA have dramatically changed the funding and financing mechanism of opioid use disorder treatment in the United States. These financing changes are reshaping the treatment of opioid use disorder in the U.S. toward evidence-based practices and value.

While the evolution of financing for substance use disorder is driving changes in care delivery, much work remains to provide integrated and high quality care to those with opioid use disorders. “Historically most opioid specialty treatment services have existed largely independent of the health care system,” notes Keith Humphreys in “The Opioid Epidemic and the U.S. Health Care System.” For those with opioid use disorder, the care system is fragmented and uncoordinated. There is little to no role for primary care screening or treatment; most patients are referred to specialists. This leads to delays in care and increased severity of the opioid use disorder by the time the problem is identified and treated. This lack of coordination produces lower quality care and increases patient suffering.

More effective would be to treat those with opioid use disorders similarly to those with other chronic conditions and to appropriately manage their care. The treatment of opioid addiction did not emerge from the health care system and that has resulted in its being poorly integrated with the rest of health care, less generously resourced, less staffed by medically-trained personnel, and less subject to the quality improvement mechanisms that are built into the rest of the health care system. People with opioid use disorders have a range of needs, some specific to their substance use and some not. These needs have historically not been well met by the health care system. While use of quality, evidence-based care such as medication-assisted treatments is increasing, there are still significant barriers to access for many. As noted above, only a fraction of those with opioid use disorder are receiving treatment for it.

One major recent shift has been viewing addiction through a medical and public health lens as opposed to a viewing it exclusively as a criminal justice problem. “[U]ntil recently, criminal policy and enforcement practices have relied nearly exclusively upon arrest and incarceration for achieving drug control,” says Amanda Pustilnik in “Legal Issues Related to the Opioid Crisis,” where she outlines the complicated legal and regulatory infrastructure surrounding the opioid crisis. The opioid epidemic is a cross-cutting criminal drug and pharmaceutical problem which involves lawmaking, policy-setting, and anti-drug enforcement.
About 1.5 million people are arrested annually for a drug-related offense; 85% of these are for individual drug possession. Mass arrests for drug possession have led to mass incarceration with dire consequences for communities, families, and tremendous cost to taxpayers. This approach has done little to reduce the supply of illegal drugs or rates of addiction. Decades of drug-related mass arrests and mass incarceration have disrupted the lives of individuals, families, and communities; kept people in poverty; and widened inequality.

Federal and state governments are increasingly recognizing the failure of incarceration as a response to illegal drug use and its potential harms and, are moving to alternative criminal processes and penalties. Major initiatives such as prescription drug monitoring programs, expanded access to naloxone, harm reduction and drug courts, (at both the federal and state levels) illustrate this shift in response. These nascent efforts and experiments are relatively recent in comparison to the institutionalized approach of incarceration and will require wider application and time to produce long-term results.

**Framing the Issue**

Five themes emerged in the group’s discussions that helped guide the development of this year’s big ideas. The themes are:

- **The opioid crisis has complex origins**
  
The opioid crisis emerged from a complex constellation of personal despair, the neuroscience of addiction, and treated and untreated pain. There is no single path to opioid addiction. Some begin using legally-prescribed opioids, become addicted, and transition to illegal sources of either prescription opioids or illicit drugs. Some begin with diverted legal opioids while others begin using illegal opioids, such as heroin. For some, acute or chronic physical pain is the reason for first use, while for others there is a desire for escape from emotional pain. Some people with opioid addiction have other substance use disorders, such as alcohol use disorder, while others do not. Opioid use disorder is a chronic condition, and the course of addiction is highly variable. Some people remain highly functional as their dependence on opioids increase, while others deteriorate more quickly, and may move into illegal activities to support their addiction.

  This complexity means there is no single response that will reverse the opioid crisis. Rather, a comprehensive response is required – one that engages all of the tools available to prevent and treat addiction. A comprehensive
response must include addressing the social malaise that leads people to misuse substances. It must include modifications to how the medical system promotes and prescribes opioids. It must make the best possible treatment available to those who have opioid use disorder. It must engage law enforce-
ment appropriately with respect to drug interdiction and the crimes people commit to support their addiction, but not use the legal system to punish people for their health condition.

• The medical system is involved in the crisis in multiple ways

The rapid growth in opioid prescriptions was largely due to well-intentioned efforts to respond to the realization that patients experience a great deal of untreated pain. The manufacturer of OxyContin promoted the notion, inaccurately, that its product had a low risk of addiction relative to other painkillers in use at the time. Opioid prescription rates in the United States far exceed those of other developed countries, which set the stage for high levels of diversion of opioids to illegal uses. A small subset of clinicians pre-
scribe opioids in large quantities and with little monitoring of patients for effectiveness or potential addiction. Limited availability of opioid treatment is due in large part to the long-standing isolation of addiction services from the mainstream medical system. Medical system reimbursement methods make it easier and more desirable to prescribe opioids than to take other approaches to pain management. The myriad ways the medical system was involved in creating the crisis means the medical system must be at the cen-
ter of responding to the crisis.

• Treatment is currently the largest gap in addressing the opioid crisis

Medication-assisted treatment -- the combination of drugs to reduce craving for opioids and therapies designed to address the social and emotional context in which addiction occurs -- is highly effective in treating opioid add-
diction. Like other chronic conditions, opioid addiction requires sustained treatment, often for a lifetime. With only one-quarter of people with opioid use disorder receiving treatment, the need for more treatment is profound. Increasing treatment rates requires increasing the number of providers of evidence-based treatment methods, reducing financial barriers to receiving treatment, and addressing geographic disparities in treatment availability. It also requires better identification of opportunities to intervene in the lives of people with opioid use disorders when they interact with the criminal justice system or social programs. No matter how successful we are in reducing the number of people with new substance use disorders, effective treatment is necessary to reduce the burden of this disease on the approximately two million people who misuse or are dependent on prescription opioids.
• **Knowledge gaps are a barrier to an effective response to the opioid crisis**
  Despite great efforts, there is much we do not know about the nature of the crisis and the best way to respond. Our knowledge gaps begin with poor understanding of the best ways to treat acute and chronic pain and how to reduce the risk of addiction. We need to know more about which variants of medication-assisted treatment are most effective for different populations. The relationship between opioid use and other substance use disorders is not fully understood. While deaths from opioid overdose are fairly well measured, the broader social consequences of opioid misuse are not as well known.

• **Partial successes need to be bolstered and spread**
  Rates of opioid prescribing are beginning to decline. In some localities, cooperation among the health care, criminal justice, and public health sectors are yielding better identification of people in need of services and referral to those services. Sustained progress will be required to convert these signs of success into a comprehensive response to the opioid crisis. Successful strategies in some locales need to spread across the country.

**Five Big Ideas to Confront the Opioid Crisis**
There is much we can do to address the opioid crisis in the United States. The Aspen Health Strategy Group offers five big ideas that will help catalyze this change.
1. **Stop overprescribing**

Opioids are easy to prescribe, prescriptions are easy to fill, and most insurance readily covers the cost of the drugs. The United States is a global outlier in the rate of legal opioid prescribing. Sometimes pain can be managed with lower cost treatments that do not carry the risk of addiction, such as over-the-counter medications. Clinicians may avoid alternative methods for treating pain, such as physical therapy, which often involve substantially higher costs to patients and may be subject to significantly more oversight by insurers.

Steps to reduce overprescribing include:

- Engage the full range of clinicians, including primary care, specialty care, and dentistry, in education regarding pain treatment and appropriate opioid prescribing.

- The Food and Drug Administration should increase its oversight of the marketing practices of opioid producers given a documented history of some firms making inaccurate claims regarding their products.

- States should adopt best practices for prescription drug monitoring programs (PDMP), including comprehensive data collection, integration with electronic health record systems, and promotion of their use by clinicians, to make them more effective. States should also work together to share PDMP data across state lines and enable uniform data entry for multi-state providers.

- Encourage continued dialogue regarding voluntary or mandatory limits on the duration of initial and subsequent opioid prescriptions.

- Continue to update clinical guidelines based upon the best available evidence regarding appropriate prescribing of opioids for acute and chronic pain.

2. **Treat opioid addiction as the public health crisis that it is**

Addiction is a chronic medical condition, not a moral failing. People with the disease need evidence-based treatment, not punishment. The past use of mass incarcerations as a means of drug control has not curbed the epidemic and instead has disrupted lives and caused societal harm.

Taking a public health approach to the crisis means:

- Drug enforcement should focus on reducing the supply of illegal opioids through interdiction, targeting excessive prescribing, and reducing drug diversion.
• Identification of people with opioid use disorder and guiding them to treatment should be the top priority for health, social, educational, and criminal justice systems. Health care providers, particularly those who provide emergency care, should view linking people with opioid use disorder to addiction services as their responsibility.

• Identification of people with opioid use disorder is particularly important within the criminal justice system, where the emphasis should be on providing evidence-based treatment.

• Opioid use disorder is a chronic disease. Treatment of people with opioid use disorder should be undertaken as a life-long endeavor with uncertain results. Relapse is not evidence of failure and should not be punished.

• Program eligibility standards should be clarified to assure that people with opioid use disorder are not denied social supports, such as public housing, solely due to their disorder.

3. **Stop the deaths**

More than 30,000 people died from an opioid overdose in 2015. Most of these deaths were accidental and almost all were avoidable. Naloxone is an opioid antagonist, meaning it blocks the effect of opioids on the brain. When administered promptly either by injection or nasal spray, naloxone can reverse an opioid overdose and prevent death. It is also available as an auto-injector, allowing people without medical training to administer it readily.

Steps to eliminate unnecessary deaths include:

• Continue the spread of the number of first responders, including police, fire, and emergency medical services, that carry naloxone and are trained in its use.

• Designate public places where naloxone can be available for emergency use, much as has occurred with automated external defibrillators (AEDs).

• Expand the number of states that authorize standing orders that permit the filling of a prescription for naloxone to keep for future use rather than for a specific patient.

• Extend immunity from prosecution for people who call for help or administer naloxone, avoiding the fear that, if they are drug using themselves, they will be subjecting themselves to legal liability.
• Reduce the availability of drugs that can be stolen or misused through improved drug return programs that enable people to easily dispose of excess drugs.

4. Guarantee Access to Treatment

There is strong evidence that medication-assisted therapy -- pharmaceuticals combined with behavioral therapies -- can reduce opioid dependence. Yet, only about one out of every four people with opioid use disorder is receiving treatment.

Achieving higher rates of treatment requires better identification and referral of those with opioid use disorder; overcoming financial barriers to obtaining care; reducing stigma and concerns about criminal and civil exposure that discourage individuals with opioid use disorder to seek care; and expanding the availability of evidence-based treatment.

Specific steps to increase treatment include:

• Retain the Medicaid expansion under the Affordable Care Act as a source of coverage for a population disproportionately affected by the opioid epidemic.

• Retain and improve enforcement of mental health parity laws that strengthen private insurance coverage for evidence-based addiction services.

• Increase the number of addiction service providers through reexamination of caseload limits for certain providers and treatment programs and greater use of advance practice nurses and physician assistants.

• Build the costs of addiction, which are borne by individuals, families, employers, communities, and taxpayers, into the price of opioids and dedicate those resources to prevention and treatment.

• Engage clinicians in the use of screening tools that help identify people with opioid use disorders.

• Encourage public and private payers to expand the use of outcome-based payment models that create financial incentives for primary care clinicians and health systems to improve health outcomes, thereby creating strong incentives to identify and treat people with opioid use disorders.

• Change federal law to remove the prohibition against states obtaining federal Medicaid matching funds for treating people with opioid use dis-
orders in residential settings with more than 16 beds (the Institutions for Mental Disease (IMD) exclusion).

- Continue to educate the public about the risks of opioid misuse and the chronic nature of this medical condition to reduce stigma associated with its diagnosis and treatment.

- Invest in the design and testing of additional models of medication-assisted treatment that expand the capacity of the current addiction treatment workforce and bring in additional service providers.

5. Invest in data and knowledge

The opioid crisis emerged in part from poor understanding of how to treat chronic pain. A robust research and data analytics agenda is needed to manage appropriate opioid use, improve pain management, and reduce inappropriate prescribing and diversion of legal opioids.

An appropriate investment would include:

- Link data across states’ prescription drug monitoring programs to avoid inappropriate prescribing due to shopping across state lines.

- Harness the separate data silos that exist across insurers, pharmacy benefit managers, and employers, to better understand patterns of prescribing and use.

- Redesign current prohibitions against sharing data between the medical care and mental health care systems that impede identification and treatment of people with opioid use disorder while retaining patient control over the information they choose to share.

- Continue to develop quality standards for opioid use disorder treatment as a means for holding treatment programs accountable and for encouraging resources to flow to high quality programs.

- Continue to build the evidence of the costs and benefits of opioid use.

- Continue to build the evidence regarding medication-assisted treatment to identify the most effective medications, and the most effective types of therapy, for different people with opioid use disorder.

- Study methods for treating pain, both acute and chronic, so prescribers and patients can select options other than opioids.
Moving Forward

We are encouraged by the attention this issue is getting and the progress that has already been made in embracing some of the ideas we put forward here. We especially acknowledge the efforts of the President’s Commission on Combating Drug Addiction and the Opioid Crisis and look forward to follow-up actions taken in response to their recommendations.

Our nation did not enter into this crisis quickly, and it will not be solved quickly. Even if we are able to dramatically reduce the number of people becoming addicted to opioids, the chronic condition of opioid use disorder will continue to afflict hundreds of thousands of Americans for many years to come. Our commitment to addressing the opioid crisis must be sustained.

Recent policy changes have helped set the stage for confronting this crisis. Mental health parity, the expansion of Medicaid coverage, and efforts across the nation to engage the criminal justice system are among the strongest platforms on which to build solutions. Coverage expansions through the Affordable Care Act, and the inclusion of mental health and substance use disorder services as essential benefits, are critical features of the current treatment landscape and they must be preserved. Threats to coverage, whether through the recent lapse of funding for the Children’s Health Insurance Program or various efforts to repeal the ACA or roll back requirements regarding substance use coverage, must be resisted if we are to make progress on this crisis.
The Aspen Health Strategy Group, with its multi-sector membership, has developed these ideas to address the opioid crisis in America. It has never been more important for all parties to come together, examine the evidence, and make strides against this deadly problem.

The Aspen Health Strategy Group hopes that these big ideas will serve as catalysts for changes in policy and practice. We have a broad array of dissemination activities planned to spread the big ideas contained in this report. The leadership of the group will share this report with officials in the U.S. Department of Health and Human Services, which houses the Centers for Medicare and Medicaid Services, the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, and other agencies. It has already shared its findings with the President’s Commission on Combating Drug Addiction and the Opioid Crisis.

The Aspen Health Strategy Group members have committed to examining steps they can take within their own institutions and organizations. They are also looking for opportunities to share these ideas with others in their own sector. Change of the scale needed to address the opioid crisis will require the effort of many. The Aspen Health Strategy Group has set out to provide leadership and looks forward to working with all who share their goal of addressing the opioid crisis.
Five Big Ideas to Improve Care at the End of Life

Background

The way we live and the way we die have changed dramatically over the past fifty years, but the medical and social systems that support us as we approach the end of life have not kept up. Institutions we rely upon -- hospitals, nursing homes, medical schools, Medicare, and others -- have, by and large, failed to evolve sufficiently to reflect the new reality. While leaders in each of these sectors are showing the way to a health care system that supports people and their families as they face advanced illness and death, the pace of change is far too slow. The consequences can be seen in the unneeded suffering of millions of Americans as they experience advanced illness and approach death.

The Aspen Health Strategy Group (AHSG) selected care at the end of life as its topic for discussion in 2016–its inaugural year. This group of leaders in and outside health care spent three days considering the topic with the assistance of subject matter experts who prepared four background papers to frame the conversation. The AHSG emerged with five big ideas to transform care for people with serious illness.

The Aspen Health Strategy Group’s mission is to promote improvements in policy and practice by providing leadership on important and complex health issues. Co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former governors and former U.S. Secretaries of Health and Human Services, the AHSG is composed of 23 senior leaders across sectors including health, business, media, and technology. More information about the ASHG can be found on the Aspen Institute website (www.aspeninstitute.org/programs/health-medicine-and-society-program/aspen-health-strategy-group).

Framing The Issue

Each year 2.5 million Americans die. About 8 million people, or 2.5% of the U.S. population, have a serious illness or multiple chronic conditions and functional dependency as they approach the end of life. As Laura Hanson explains in “Over-
view of the End-of-Life Experience in the United States,” the quality of end-of-life care is a major public health concern.

Diane Meier begins “Care at the End of Life” with a reminder that “[o]ur [health care] payment system was designed in the 1960s, when long life with multiple chronic conditions was not the norm.” Medicare benefits largely determine what care is provided and paid for at the end of life because, with more than 70% of deaths occurring among those age 65 and older, Medicare is the predominant payer for end-of-life care. Medicare covers medical services, not the social supports so many people need. The traditional reliance of Medicare on fee-for-service payment supports separate silos of care, and has discouraged care coordination, increased fragmentation, and created incentives for delivery of more services. For patients at the end of life, this means receiving potentially unwanted and unnecessary aggressive interventions that can result in increased hospitalizations with little regard for the patient’s or family’s preferences. Having a care plan or a surrogate to speak for the patient can help, but neither provides a guarantee of better care in a fragmented, unaccountable health care system.

Medicare’s primary coverage of services for those at the end of life is through the hospice benefit. The benefit is limited to individuals with a terminal diagnosis who also meet other specific conditions. A person using the hospice benefit receives care according to a plan that may include medical supplies, an aide or homemaker, a social worker, grief counseling, and other services. But the benefit does not cover all service needs, nor does it cover most long-term services and supports, such as assistance with cooking, bathing, dressing and other activities. Medicare offers little coverage of palliative care -- an interdisciplinary specialty focused on improving quality of life through relief of pain and stress -- outside of the hospice benefit. Palliative care is designed to benefit people with serious illness, even if they do not have a terminal illness.

As causes of death have shifted to the consequences of chronic conditions, the “end of life” is often a slow decline with gradually increased functional dependency. Improved treatment has made diseases such as cancer, once a death sentence with a fairly predictable, rapid decline, a chronic condition with, for many, a long life expectancy and unpredictable likelihood or timing of death. The leading cause of death, heart disease, is now often a long-lasting chronic condition prior to an acute episode leading to death.

Fewer people die in the hospital than in the past, but the shift away from hospitals has led to fragmentation and difficult transitions, as people move to and from their home, a nursing home, a hospital intensive care unit, a rehabilitation unit,
and elsewhere. Hospital visits and use of intensive care just prior to death remain high. As Hanson notes “the intensity and cost of treatment in the final phase of illness continues to increase, strongly suggesting that many patients’ desires for a ‘good death’ are not incorporated into the care systems that serve them in this final phase.”

“The central guiding principle of the United States framework for treatment decision making near the end of life has been a patient’s right to self-determination,” says Mildred Solomon in “Doing Right By the Seriously Ill: Ethical Norms for Care Near the End of Life.” One might imagine that this ethos would create a solid foundation for meeting patient and family needs at the end of life. Advance directives and other forms of advance care planning -- documents designed to capture a patient’s wishes -- are a way for patients to ensure that their wishes and goals are taken into account as they approach the end of life with a serious illness. But, Solomon notes, there are inherent social and cultural barriers to planning for the end of life. Despite decades of promotion, only about a quarter of adults have an advance directive. In a recent shift Medicare announced that it would pay physicians for advance care planning conversations with beneficiaries. Data are not yet available, however, to tell us whether or not this policy has increased uptake.

But the ethical challenges surrounding end-of-life care are more pronounced. “The emphasis on autonomy has not achieved its goal of ensuring truly informed choice,” according to Solomon. This is due to the fragmented approach of considering each intervention one-at-a-time rather than taking a more holistic approach to patient and family preferences and goals. With a broader perspective, patients’ and families’ social, emotional, and spiritual needs rise to be on par with or above their medical needs. Solomon describes how “relational ethics” would place patient choice within the context of the social and emotional needs of patients and their loved ones.

The powerful role financing plays in how Americans experience care at the end of life is affirmed by Haiden Huskamp and David Stevenson in “Financing Care at the End of Life: Ensuring Access and Quality in an Era of Value-Based Reforms.” They begin their paper with these words: “The manner in which end-of-life care services are financed is a key determinant of access, quality, and cost of care delivered to individuals as they approach death.”

Many payers, and particularly Medicare, are moving toward bundled payment models and value-based payment systems. That is, rather than paying individually for each service, a single payment is made for an entire episode of care
Improving Care at the End of Life (bundle) or tied in some way to the quality of the outcome for the patient (value-based). Medicare is currently testing a new payment model for hospice care. The Medicare Care Choices Model allows beneficiaries to receive hospice support services alongside curative treatment. Under the demonstration, hospice providers are paid a fixed monthly fee per beneficiary to cover some hospice services, while other services are paid separately.

Huskamp and Stevenson note various limitations of the transition to new payment models. Hospice and palliative care are often carved out or left out of other value-based payment reforms, inhibiting their integration into new care and service delivery models. The absence of meaningful quality measures related to end-of-life care makes it difficult to pay for quality or value.

Huskamp and Stevenson also describe the critical role that Medicaid plays in paying for social supports excluded from the Medicare benefit. Yet, Medicaid eligibility is limited to those with the lowest income and fewest assets, coordination between Medicare and Medicaid is weak, and Medicaid’s long-term services and supports are designed for people with disabilities and frail elders, but not particularly focused on those with advanced illness nearing the end of life.

Meier outlines a number of barriers to improvements in end-of-life care, but also sees opportunities for improvement. Along with changing what we pay for and how we pay for care, Meier highlights the important role quality measurement must play in motivating change. “When asked what is most important to them, the majority of older persons prioritize remaining independent and free of disabling suffering such as pain, shortness of breath and other sources of symptom distress. They rank ‘living longer’ last among these 3 priorities.” Ultimately, Meier concludes, “[a] major multi-sector financial investment in measure development, testing, and implementation is needed to honor our commitment to assuring quality for the most vulnerable and those least able to advocate for themselves.”

What Do Americans Need?

During the AHSG discussions, several principles emerged to guide the group toward ideas that improve care. Those principles are as follows:

- The voice of the patient and family should guide care as people face serious illness and approach death.

All health care should be patient-centered, but no phase of care is more personal than that which occurs as a person approaches death. Preferences regarding
measures to be taken to prolong life, willingness to submit to procedures with highly uncertain outcomes, and how to maintain personal autonomy and dignity are highly variable. The best decision for the patient and family is the one selected by an informed and supported patient and family. And while the term “family” is used in this paper, it is important to note that family members are often not aligned among themselves in their views, and in some instances the patient may prefer that a loved one outside the family unit be the person who guides care.

- Health care institutions should engage patients and their families in determining a course of care and should not provide care that is not needed or not wanted.

Health care institutions should ensure patients are well informed of the health and financial costs and benefits of potential interventions at the end of life. Health care providers should respect the guidance they are given by patients and their families. Effective communication entails more than filling out a form or obtaining a signature. Effective patient-family-provider communication -- combined with coordination among those who provide services -- can reduce unwanted services and procedures. Health care institutions should not provide services that a patient does not want.

- Public and private insurance benefits should reflect the social and coordination needs people have as they experience serious illness and approach death.

Insurance is designed to protect people from the financial risk associated with an unfortunate occurrence and help assure access to needed services. People with serious illnesses often have social and coordination needs that go along with their medical needs. Family members may need respite care, patients may have difficulty preparing their own meals, and navigating complex medical and social systems may exceed the capacity of the patient and family. These needs -- and the resources to pay for them -- are often at least as important to the patient as the need for medical services.

- The health professions workforce should have the skills to provide patient-guided care as a team for patients with serious illness and approaching death.

The growth of palliative care as a specialty and team care as a core competency are promising developments but ones that are proliferating too slowly to meet the rapidly growing needs of an aging population. Medical education has been slow to adapt to evolving patterns of mortality and morbidity.
Community resources should be supported and engaged to make planning for the end of life a normal part of life.

Preparation for respectful and dignified care at the end of life requires a process that engages people long before they are ill and evolves as their lives and health conditions change. The medical care system’s interactions with a patient are too infrequent, and often too focused on a particular acute episode, to bear the full burden of eliciting evolving patient preferences. To be effective, engagement on this issue requires the involvement of a variety of community institutions, such as religious groups, voluntary associations, educational organizations, and others.

Five Big Ideas to Improve Care at the End Of Life

Care for people with serious illness approaching the end of life needs to change. The AHSG offers five big ideas that will help catalyze this change.

1. **Build the development and updating of an advance care plan into the fabric of life.**

Engaging in advance care planning should be as natural as thinking about one’s financial future. An advance care plan (also known as an advance directive or living will) outlines a patient’s wishes for treatment when he or she has a serious illness and may be unable to make his or her own decisions or speak for him or herself. The plan may be based upon a template, many of which already exist, or it may be highly tailored to the individual. An alternative is the naming of a proxy—a person who has the authority to make care decisions based upon their knowledge of the patient’s wishes. The creation of an advance care plan or the naming of a proxy requires conversations between patients and their families and doctors, other clinicians, and those outside the health care sector. Given the taboos surrounding death and the awkwardness many feel considering and discussing it, a cultural change will require engagement of many sectors.

The AHSG considered a broad array of actions that would normalize the advance care planning process:

- Create a standardized, self-guided advance care planning tool that people can use to orient themselves to the issues involved and begin the process at their own convenience.

- Build incentives into public and private insurance plans to encourage people to develop a plan, particularly at critical points such as the time of enrollment.
or at open enrollment. Medicare, in particular, could be designed to require or encourage enrollees and/or their providers to have a plan in place at or near the time of enrollment.

• Integrate planning tools into commonly used technology platforms, such as smart phones.

• Model the importance of advance care plans by having everyone in the health care workforce develop their own, thereby making it easier to initiate a conversation with their patients.

• Encourage large employers to build development of advance care plans into their employee benefits programs.

• Build into all of the above options mechanisms to update the plan at regular intervals and particularly, at the time a person is diagnosed with a serious illness.

2. Redefine Medicare coverage in a way that meets the complex needs of people with serious illnesses.

As the largest payer for services needed by people with serious illnesses and approaching the end of life, Medicare has unique power to shape the organization and delivery of services. Rather than focus exclusively on those with a specific terminal diagnosis, as is required to receive the hospice benefit, Medicare could provide additional benefits to those with advanced illness, defined by the Coalition to Transform Advanced Care (CTAC) as “occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact . . . a process that continues to the end of life.”

There are two large gaps in Medicare coverage for people with serious illness. Medicare provides no coverage for social supports, including respite for family caregivers (other than a very limited benefit as part of the hospice benefit) and help with activities of daily living. In addition, while covering myriad individual clinical services, Medicare provides no coverage for the types of care coordination that become increasingly important as people’s medical conditions become more complex.

Whatever changes Medicare makes to improve care for those with serious illness must be aligned with the broader movement by Medicare to promote the organization of the health care system into accountable groups -- systems of providers
including hospitals, physicians, clinicians, post-acute facilities and others -- that receive a single payment for an episode of care or to cover the total cost of caring for a defined population. Medicare has several demonstrations promoting this shift, and almost one-third of Medicare enrollees are in Medicare Advantage plans, which receive a fixed monthly payment for each enrollee.

The AHSG considered three changes in Medicare policy that would fill in some of the current gaps in coverage:

• Medicare should include a benefit available to those diagnosed with an advanced illness that provides social supports and care coordination through a defined care team. This new coverage would provide strong incentives for providers of care to people with advanced illness to form into teams organized to meet the needs of patients, thereby reducing the fragmentation that such people often experience. Unlike the Medicare hospice benefit, which is dependent upon a diagnosis of limited life expectancy and the enrollee foregoing curative care, eligibility for this benefit would only depend upon diagnosis with an advanced illness.

• Medicare (and Medicaid) should experiment with models that encourage organized systems of care to invest in changes that yield coordinated, patient-centered care for people with advanced illness. Such investments could include enhanced information technology systems that promote coordination, training for care teams, and improved efforts to understand patient preferences. These experiments could use incentives similar to those being given to Accountable Care Organizations (ACOs) to organize, integrate, and reengineer care within a financial model that creates opportunities for rewards when the system is successful in controlling costs while preserving or improving quality.

• Medicare should test integration of the hospice benefit into Medicare Advantage and other Medicare demonstrations. Leaving out these benefits from new care models provides little incentive for improving efficiency and delivery of care to those with serious illnesses. Integration of the hospice benefit would provide greater opportunities for innovation, care coordination and improvement in care quality.

While all of these options are directed to Medicare, many of the same proposals, or at least the same concepts, can also be applied to commercial insurance.
3. Develop a set of quality metrics related to end-of-life care that can be used for accountability, transparency, improvement, and payment.

Quality measurement and reporting are integral to efforts to improve care for people with advanced illness. Measurement allows patients and payers to demand and reward better performance. Measurement also allows providers to benchmark their own performance and learn from leaders. And measurement is essential as payment models change to determine if those changes yield improvement. Quality metrics related to end-of-life care are also critical to the integration of hospice and palliative care into the broader Medicare financing and delivery reform efforts as mentioned above.

The quality measurement enterprise in health care is always complex, but there are particular challenges in the area of end-of-life care. At the end of life, a primary quality metric is adherence to patient wishes, not adherence to predefined care protocols, as may be the case with more routine matters. Much of what is required to provide high-quality care involves communication and coordination—concepts that can be difficult to measure. And clinical outcomes or improvements in health status, which form the basis for many quality measures, have limited applicability at the end of life.

Federal agencies and independent organizations play a significant role in developing, validating, and proliferating the use of quality measures. Government programs can provide a source of funding for measure development and reporting. Given the critical role of patient and family experience in assessing the quality of care at the end of life, a national effort will be required to finance and build the infrastructure necessary to collect quality data. Such an effort might include:

- Develop and validate a standard measurement set that reflects a patient’s preferences and the family’s experiences and how well health care and social services support them.

- Develop methods for collecting, reporting, and using end-of-life quality measures across diverse care settings, to enable policymakers and providers to evaluate the effectiveness of different approaches.

- Include end-of-life quality measures in federally-sponsored reporting systems, such as Nursing Home Compare and Hospital Compare, so that patients and families can better select providers on the basis of the quality of care they are likely to receive.
• Develop benchmarking, training and feedback systems to enable providers and care systems to improve the quality of services provided.

4. **Increase the number and types of health professionals who can meet the growing needs of an aging population.**

Graduate medical education includes little training on the needs of patients in the last years of life. Only about 20% of residents plan to work in primary care and less than 1% of physicians pursue fellowships or training in geriatric or palliative medicine. Access to palliative care is largely dependent on hospitalization, leaving out a large segment of the population that lives at home or in long-term care settings. There is a need to train additional doctors, nurses, nurse practitioners, social workers and others in palliative care. Similarly, payment policies should reflect the diverse array of providers needed to deliver high quality palliative care. Larger bundles of payment may facilitate this shift as organizations allocate their payments across providers without the strictures of the Medicare fee schedule. The gap between workforce needs and realistic supply given current circumstances is so large that a multifaceted approach is necessary.

Improving care for those with serious illness requires addressing shortages of professionals with expertise in geriatrics, palliative care and primary care. Creation and recognition through Conditions of Participation of new provider types, such as Advanced Primary Care Practice (APCP), and payment methods that explicitly cover the costs of multidisciplinary teams, would be powerful levers for bringing more providers into the field by assuring the resources they need to do their jobs effectively. Leadership from Medicare could blaze a trail that Medicaid and private insurers could follow.

The AHSG considered four approaches to address workforce needs:

• Create financial and professional incentives to expand the number of health professionals trained in palliative care.

• Integrate understanding of palliative care into the educational experience of all health professionals.

• Establish interdisciplinary training programs designed to develop teams that are expert in palliative care.

• Expand the types of professionals, including community-based workers, who can play a role in providing patient-centered end-of-life care.
5. Support model communities embracing fundamental change in the design and delivery of care for people with advanced illness.

A care system that meets the social needs of people with complex illness must reallocate resources from clinical care to social supports. Such a transformation involves substantial disruption of existing financial flows, and would typically garner significant opposition from those succeeding in current care models. This opposition can only be overcome if the transformation arises from a social consensus developed at the local level.

The AHSG considered the elements that must be in place at the local level to effectuate such a transformation. In addition to a strong local civil society, communities will need educational tools for the citizenry, and perhaps a standardized curriculum to demystify end-of-life issues and create a common language for discourse. Yet, even with these elements in place, communities are limited in what they can do because of the strong financial leverage of state and national programs, insurers, and health systems.

Given the hurdles communities will face in tackling the challenges associated with redesigning end-of-life care systems, those communities that rise to the challenge should be supported in their efforts, and their successes (and lessons from their failures) should be shared with others attempting the same sorts of changes. Community supports could include national recognition, development of a collaborative network to support such communities, and resources to learn from and teach other communities making similar efforts.

Moving Forward

The Aspen Health Strategy Group hopes that these big ideas will serve as catalysts for changes in policy and practice that yield real improvements in end-of-life care. A broad array of dissemination activities is planned to spread the big ideas contained in this report. The leadership of the AHSG will share this report with officials at the Centers for Medicare and Medicaid Services (CMS), the National Academy of Medicine (which is in the midst of a major initiative related to end-of-life care), and the new Administration.

The AHSG members have committed to examining steps they can take within their own institutions and organizations. They are also looking for opportunities to share these ideas with others in their own sector. Change of the scale needed to reorient care for those with advanced illness to the real wishes and needs of patients and families will require the effort of many. The AHSG has set out to
provide leadership and looks forward to working with all who share their goal of promoting improvements in care for Americans approaching the end of life.