

Healthcare's Hard Choices (and How to Stop Avoiding Them)

Penn President Amy Gutmann and PIK Professor Jonathan Moreno on their new book, which traces the history of bioethics and tackles some key issues in healthcare—from thorny moral questions to the frontiers of science and the most bitter divisions in American politics.

Interviews by John Prendergast

Everybody Wants to Go to Heaven but Nobody Wants to Die—Amy Gutmann and Jonathan D. Moreno’s evocatively titled examination of “bioethics and the transformation of healthcare in America”—covers a lot of intellectual, historical, and philosophical ground. That’s in keeping with the authors’ broad knowledge and long experience with the field.

Gutmann, a political theorist and expert on deliberative democracy, is of course Penn’s president and also serves as the Christopher H. Browne Distinguished Professor of Political Science and Professor of Communication. Bioethicist and historian Jonathan Moreno is a Penn Integrates Knowledge Professor with ap-

pointments in the departments of medical ethics and health policy, history & sociology of science, and philosophy, and is the David and Lyn Silfen University Professor. Both have written extensively on bioethics issues and have spent decades teaching it in the classroom. And from 2009 to 2016 Gutmann chaired Barack Obama’s Presidential Commission for the Study of Bioethical Issues, on which Moreno served as a senior advisor.

But the book—published by Liveright, a division of W. W. Norton, in late August—opens on a strikingly personal note, with a pair of stories from the authors that “help to explain why we care so much about bioethics” and also to vividly high-

light the “doctor knows best” medical culture that prevailed through the middle decades of the 20th century.

Gutmann shares a childhood memory of how doctors pressed her mother to give them permission to amputate her beloved grandmother Eva’s gangrenous leg, even though, while in pain, “she was fully conscious and capable of understanding the situation.” Her mother’s insistence that they allow Eva to make that decision herself—she consented, but died days after the operation—made Gutmann realize “how she treated everyone with the respect they deserved—which meant, when necessary, not being unduly deferential to authority.”



Similarly, doctors at first told Moreno's mother, Zerka, who was suffering from a rare cancer of the bone, that the problem was arthritis. After that story could no longer be sustained, and she'd undergone unsuccessful radiation therapy, they left it to Moreno's psychiatrist father—a "brother physician"—to inform her that her arm would have to be amputated. Even after that, Moreno's father never shared the information—which his mother learned only when she found a letter to him from her surgeon—that "if her cancer didn't return in five years, they could consider her cured."

"Eva and Zerka faced their medical crises just a few years before generational changes transformed the contours of the ethics underlying modern medicine," they write, pointing to a signature aspect of bioethics: promoting a more patient-centered approach to healthcare, in which physicians have a duty to tell the truth to patients and to listen to what they have to say (still a work in progress, they note).

From this starting point, the book goes on to examine the often neglected subjects of public health—from the introduction of the polio vaccine, to the use of fluoridation to reduce cavities, to the ongoing problem of skepticism over vaccinations—and the devastating personal and societal effects arising from the undertreatment of mental illness. It also examines from all sides high-profile debates over the right to die and end-of-life care, the morality of "nudging" as a means to encourage desired behaviors, new technologies for reproduction and disease prevention before birth, and the serious risks and immense promise of gene-based techniques for fighting cancer and other conditions. Perhaps above all, the book engages deeply and thoughtfully with the central conundrum of America's health-care system—which continues to nurture some of the world's most important and technically complex lifesaving innovations in medicine without being able to come to agreement on how (or if) to provide basic health insurance to all of its people.

In separate interviews, *Gazette* editor John Prendergast asked the authors about what it was like to collaborate on the book, some of the key issues it raises, and what they hope readers will take away from it. Their responses have been condensed and edited.

In the introduction, you say you thought you could write a "far richer account" together than separately. What did your coauthor bring to the project that was particularly valuable?

Jonathan Moreno: Well, Amy is a political philosopher. And I'm somebody who has been more focused on emerging technologies and ethics and law and the way that those new developments relate to [the] history of whatever scientific or technological field I'm interested in. So we brought the political philosophy together with the history. And I think it's evident that we had a good dialogue about that in the book—without, I think, it being "lumpy." You can't turn the page and say, 'Oh, here's Gutmann, and now here's Moreno.' We actually had such a back and forth that we ended up blending our thoughts.

Amy Gutmann: Our work together on President Obama's Bioethics Commission laid the foundation for our collaboration on this book. As chair of the commission, I was impressed by how Jonathan's unique combination of historical, cultural, and philosophical insights complemented my insights as a political theorist and leader of a large academic medical center and health system. Also, since both of us have been working in bioethics since the 1970s, very nearly at the beginning of the field, we witnessed most of these transformations in real time. So we have that story to tell as well. The two of us represent just a fraction of the astounding diversity of approaches and interests in bioethics at Penn, which we also draw upon. On top of all these reasons, it turned out we really enjoyed coauthoring. The lively conversations we had no doubt also contributed.

While it's better to have health information than to be kept in the dark as your relatives were, what might be some of the drawbacks to the assumptions physicians and patients are operating under now?

AG: We now widely recognize that patients come first in medicine, that both their lives and their perspectives on life count. But that certainly doesn't mean that doctors and nurses are simply conduits of information and technical expertise, doing whatever their patients want. Patients benefit enormously when healthcare providers wisely advise them not just about drug regimens and treatments but also about healthy habits. Most patients want to make choices that draw on the expertise and experience of doctors and nurses. The problem today is that grueling clinical regimens and under-compensation for spending time with patients prevent most expert caregivers from giving their patients the time and attention they need and deserve.

We *can* have it both ways. It doesn't have to be all one or all the other thing. We can respect patient autonomy and we can also enlist the expertise and knowledge of the doctor in helping guide the patient to a good, individualized decision.

A perfect example that's very much in the news is the debate over vaccination. While we have increased access to expert information, we also live at a time when, for some, expertise has become a dirty word (and as we recount in the book, some "experts" were actually frauds). Doctors are not moral authorities, but we and our children will live healthier, longer lives when we are guided by the medical knowledge that ethical, well-educated doctors and nurses possess.

JM: I think it's almost exactly 20 years since a physician colleague walked into my office with a piece of paper that his patient had printed off the internet and said, "Doc, this is what I want." And he was bemused and troubled—because we both knew where that was going, right?

“Bioethicists led and responded to a scientific and medical revolution because someone had to do it.”

You used the word “information.” To be somewhat wonky about it, there’s a lot of information, but there’s not a lot of knowledge. And that is a problem. We’re seeing that, frankly, in the vaccination debate. There’s a lot of information. Some of it’s good; some of it’s not. But it doesn’t add up to knowledge. So that is a downside. It does put more of an onus on the patient. I don’t like to think of patients as consumers because, if you’ve been sick, or if anybody you love has been sick, it’s not like going to buy a car [and you end up haggling]. It’s just not. It’s not a level playing field, at least emotionally.

One other related thought about the downside: it may be better now, but I’ve heard from friends who were patients, who asked their doctor, “Well, what would you do, Doc? I’ve got a few different options,” and the doctor answered, “I can’t tell you. You have to be autonomous.” And so that was like, “Oh, my god—this is a triumph of bioethics over common sense.” By the ’90s the principle of respect for autonomy had penetrated the culture to a great extent, but it also had gotten distorted. There was sort of an overreaction.

It’s also true that that problem is exacerbated by the fact that doctors aren’t paid for what are called “cognitive services,” for the most part. The first time you see a new doctor, he’ll give you about 15 minutes. And after that it’s eight minutes. So these are problems. These are the downsides. But in an era when we do know so much more and have so much more access to information, these are kind of inevitable problems. And again, as healthcare gets more expensive and doctors’ time gets more precious, it just makes it worse.

You write that bioethics as a discipline has come to prominence at the same time that, in general, popular faith in institutions and authorities has been declining. Why do you think that is?

AG: At the same moment that the efficacy and the cost of healthcare are increasing, people’s trust in institutions is generally decreasing, precipitously so

from the 1960s onward. Bioethics came to prominence during this time in part because it navigates between these two trends: it asks hard but critically important questions about equity and access, respect for autonomy and benevolence, and that’s why it rises to the fore in our collective consciousness. Bioethics mediates some of these decisions in each of our minds and our lives. Bioethicists led and responded to a scientific and medical revolution because someone had to do it.

Bioethics is an academic field that is intensely interested in practical, real-world questions that affect every stage of everyone’s lives, from bringing children into the world to exiting the world with dignity. Its broad visibility arose in part because of an ironic historical and societal twist: as medicine becomes more expensive and more effective and the ethical questions become manifold, people begin to doubt it along with other societal institutions. The ethical questions raised by modern medicine became inescapable and our lives often literally depend upon answering them well.

JM: I think bioethics is a more intensified version of the kitchen table conversations that people have. You know, when the first so-called “test tube baby” is born, people go, “Hey, that baby came out of a test tube. That’s really weird, you know?” And in a certain sense that’s the conversations bioethicists were having, too—except they had a lot more sentences than that, and they would refer to classical sources. But the issues are the same: What is it to be a person? And what are the implications for family life?

Bioethics has gotten hotter because the topics have gotten hotter. And bioethicists—especially in the early days, when they were called “self-appointed experts”

and so forth—I think were just people who managed somehow to jump into that conversation and spend more time on it than others. It was a response to a felt need. And it was a response, of course, in the background, to new technologies, social destruction, all the other stuff like Vietnam, Watergate, and the sense that society was changing really fast.

Given all the factual evidence to the contrary (see excerpt on page 38), why has the myth that the US has the “best healthcare system in the world” persisted so long?

JM: Well, we’re really good at making stuff. You know, making stuff is what Americans do really well, historically. But that doesn’t translate into great healthcare. That translates into great healthcare *stuff*.

We’ve been good at avoiding hard choices for a long time. And we’ll probably be good for a while longer, unfortunately. But it’s not sustainable.

We have great people at places like Penn who are funded partly by NIH to come up with better and better ideas. And they actually turn into stuff. The best example of that is what’s generally called “genetic engineering.” We are in the 20th anniversary of the Gelsinger case [in which Jesse Gelsinger died as a result of his participation in a gene-therapy trial at Penn], and we recognize that, and that’s a painful episode, and it’s been hard—but now things are really moving fast.

So there has to be a way to address this, and it involves not only political pressure, but it also involves some creative legislators. In the book we talk about some people who were willing to take positions in the ’60s, and we need something like that again.

It's just not sustainable, and it exacerbates inequality, and it's what everybody worries about. It's a cliché, but it's true: if you're a working person, one medical catastrophe can do in every part of your life. Everything, from your marriage or your relationship to your work. So it's frustrating.

AG: The US has been enormously innovative. We have incubated an amazing array of new biomedical devices, new drugs, discoveries, and therapies. We—both academic medical centers like Penn Medicine and our nation generally—have been setting the global pace for advances in healthcare. Many of the most dynamic biomedical research communities and the most dynamic and innovative biomedical research discoveries find their home here. Given the global competition, however, this historic trend will only continue if the pace of government investment in basic and biomedical research picks up.

But—and here's the big “but”—despite the fact that the US spends more than any other industrialized nation on drugs and medicine, Americans don't even have universal access to basic healthcare. That's why the myth is increasingly fading in popularity.

We are leading the world in many different aspects of healthcare innovation and in access to that innovation for the affluent—which helps account for the myth—and yet in so many ways we are lagging the world in healthcare access, affordability, and measurable healthcare outcomes for the majority of Americans, which accounts for the increased questioning and fading of the myth.

Our response to this paradox of admirable innovation coupled with bad aggregate outcomes: equity and affordability of healthcare can and should go together. We can—indeed we must—make progress in ensuring equity in healthcare and in advancing prevention of disease over treatment. And *when* we do so, because I believe that we *will* do so, healthcare will become *more* affordable, individually and collectively. Americans don't want to—and

we don't need to—dispense with all of the amazing things that are going very right in this country. We can strengthen our commitment to innovation in effective biomedicine as long as we attend to equity in its cost and distribution.

To further advance the cause of universal coverage and universal access, we need to get drug costs under control. We need to invest in public health and we need to improve access to prevention as well as to innovative and novel therapies. As soon as we muster our collective will, we can and we will find a way to do all of these things.

JM: On public health, American bioethics, more than the rest of the world, has been very high-tech oriented. And public health is not. And so we wanted to elevate public health [in the book], and particularly mental health. Because, again, you just walk around, you see the consequences of our failed mental health system. If people are living on the street, some significant proportion of them have treatable mental illness or a diagnosis of mental illness. And then upwards of 20 percent, maybe more, people who are in the prison system. So that was one thing that was really important to us.

AG: In America, we have a misunderstanding of what the term “public health” means. We tend to think of it purely in terms of a department of public health in a city or a county, and in particular, we think of public health as healthcare for people of limited means. This is not what clinicians, researchers, and policymakers are describing when they talk about public health. What they mean is the public's health overall and the health of populations and communities over long periods of time.

It's worth repeating the central paradox or the central dilemma in American healthcare: some have access to the best healthcare in the world, but only some. Increasingly in America, populations of people are not making progress—in fact, for some segments of the population, for the first time in generations, life expect-

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EXCERPT

Weighing the Price

Making healthcare choices tests our priorities, moral values, and willingness to work out disagreements.

By Amy Gutmann and Jonathan D. Moreno

Everybody Wants to Go to Heaven, but Nobody Wants to Die is the title of an old blues song that captures the ironic way American society has come to view the afterlife, an ideal place where no one has to pay the price of achieving eternal perfection. In reality, though, our life choices test how much we are willing to pay. For healthcare, the stakes are high: longevity, the quality of life, and often life itself. When the stakes are so high only the best will do, but “the best” has to compete with all the expenses and other hard choices involved in getting the best.

To take the most glaring example, there's no limit on healthcare spending in the United States. We spend far more per capita on healthcare and medical science than any other society, an amount that continues to grow. If the results corresponded to the spending, there would be little reason to complain. Unfortunately, all that money hasn't made us the world's healthiest country—far from it. Compared to the populations of other high-income countries, Americans today have among the lowest life expectancy and the highest infant mortality. The United States spends about twice as much per capita on medical care as other affluent countries, providing insurance to a lower proportion of its population. American healthcare is inefficient and inequitable, the worst of both worlds.

Technological innovations coupled with other societal changes raise other hard questions—for example, about new means of human reproduction and their implications for the well-being of children, as well as the liberty, responsibility, and sometimes even the identification of parents. The health and longevity for which we strive have never come without public controversy, while also creating tough choices among competing values. We must face up

to the fact that spending more on healthcare—both as a society and as individuals—means spending less on something else we value, like child care; elementary, secondary, or higher education; public or private transportation; housing; or discretionary quality-of-life goods and services. Those hard choices are inevitable, and the costs aren't only financial. Whether exemplified by divides over universal healthcare insurance, investments in public health and mental health, new reproductive technologies, genetic engineering, end-of-life care, or organ donations, making healthcare choices for ourselves and our society tests our priorities, our moral values, and our willingness to work out our disagreements.

There are also rare and remarkable times when we actually serve up the best and don't feel any need to do tough thinking about tradeoffs. As we were writing this book we were transfixed by the rescue of a Thai youth soccer team and their young assistant coach from the cave that flooded and trapped them for over two weeks. Hundreds of rescuers from around the world were mobilized, from Thai Navy Seals to an international group of volunteers. Once rescued, the team and coach were helicoptered to the nearest city's hospital quarantine for a week. No expense was spared; no knowledge or expertise untapped. A volunteer diver heroically lost his life early in the rescue operation.

What makes situations like these so exceptional? The life-and-death stakes are immediate. The lives are identifiable and we positively relate to them. ... Human psychology is geared to identifiable victims in need of rescue. Most of what produces the everyday healthcare we need, however, is the product of making the hard choices that bring about longer, healthier lives for everyone. Contrast the Thai rescue, where nobody questioned whether it was worth the all-in cost of rescuing 13 people, to the US Congress's unwillingness to fund health insurance for all Americans, and to what happens every day in the United States with respect to healthcare for millions of low-income, vulnerable residents of our country. How much healthcare spending in the United States is consumed by emergency room visits is a matter of debate (somewhere between 2 and 10 percent), but even if we knew the exact amount, would anyone want to deny true emergency care, even at the risk of some people using the ER for routine care? Going all out in emergency situations is a testament to human compassion, but routinely using the emergency room to care for millions of uninsured is evidence of a wasteful, inhumane healthcare system. We want to explore how in normal times, when the stakes are extremely high for millions of people but not so immediately obvious, we can ethically address healthcare's hard choices.

In ages past, when it came to longevity and health, people usually had little choice and so turned their eyes skyward, hoping for the best. Today, by contrast, medical science's power for good is vastly greater than even just a century ago. Infectious diseases like polio, smallpox, measles, mumps, and diphtheria then were

common killers. Now vaccinations and antibiotics have either eradicated or radically decreased their incidence. Even more significant are public health measures like clean water, regular food supplies, and other environmental improvements that with antibiotics and science-based therapies for diseases like stroke, cancer, and heart disease have created remedies that would have seemed like science fiction only a century ago. To take just one familiar measure of life expectancy change over the past century: an American born in the early 21st century is likely to live to 80, whereas one born in 1900 had a life expectancy of only 47 years.

All stages of our lives are caught up in challenging ethical questions raised by modern medicine, healthcare, public health, and life science research. Here's just a sampling of the bioethical issues that we raise: Do we want to live in a society that nudges us toward greater public health by incentivizing the healthier

“Bioethics involves high stakes for everyone, and requires informed reasoning, not heartless rationality.”

among our choices? And if so, how do we want to be nudged and by whom? What legal means would we support to enable individuals to exercise more control over their deaths as well as their lives? As we are all able to live both longer and healthier lives, who should receive and pay for what kind of healthcare? What responsibility should individuals and communities take for the health of one another and for future generations? When some lifesaving treatments like organ transplants are scarce, how should our society decide who gets access? Absent evidence of the efficacy of a treatment, when should experimentation on humans be permitted? Once a treatment is found to be effective, who should benefit and at what cost?

Answers to these kinds of questions can be lifesaving, life extending, and life enhancing, or they may hasten the end of life or diminish its quality. That's why we think it's so important to attend to the ethics of healthcare, public health, and life sciences research—the field known as bioethics. Bioethics involves high stakes for everyone and requires informed reasoning, not heartless rationality. Not merely an individual enterprise but a social one, it also calls on us to think through issues together. When we work to improve medical care and advance medical science, we create a more moral politics that relies upon our collective search for a common good.

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Extra

Online: Gutmann and Moreno on the contested meanings of “death with dignity” and the ethics of “nudging.”

tancy has actually declined. We have deep and profound inequities, and major issues of affordability.

How can we, in this country, provide better and more effective healthcare for more people over longer periods of time in a fiscally responsible way? That is a fundamental question of public health, of the *public's health*. What we want people to come away from this book thinking about is not only how they can make good decisions for themselves and their families in moments of urgency or crisis. We aspire to a deeper insight: How do all of us, as citizens of this country, think about improving the public's health in this country in just and durable ways, meaning ways that are ethically justifiable, scientifically valid, politically possible, and financially sustainable?

On some highly contested issues, you describe smaller actions that might be agreed upon—concerning the right to die, supporting hospice care; with the healthcare system, calling for clear and itemized medical billing and price accountability. Are those just good things in themselves, or do they have a larger value as well?

AG: If we look, we will find many more ways to agree despite our ongoing disagreements. Making hospice care more accessible is one important example of strong convergence among otherwise competing ethical perspectives. Peacefully and productively sharing a society together is really about finding points of overlap, convergence, and agreement with those with whom we have a lot of profound disagreements.

Take the critically important goal of advancing healthcare reform and health equity. Many Americans today see these as big polarized and polarizing issues where consensus and compromise may

be impossible to achieve. Something that my political science research and my experience leading a large, multifaceted university with over 40,000 employees has taught me is that we can work productively to find areas where we can agree and work from there. One practical maxim that I live by as both a democratic citizen and a university leader—“don't let the perfect become the enemy of the good”—isn't at its root a call to compromise. It's most fundamentally a call to get as many good things done as possible for all those whose lives and livelihoods depend on us. That's the mission that gets me up every morning and that also guides our recommendations in this book.

JM: We're not just writing a philosophy book. We're writing a book that we think has specific things that the culture can do, society can do, to political actors and so forth. The billing issue could go a long way, if there's enough pressure, to helping institutions figure out what costs what. There's such a difference between pricing and billing, and even institutions seem to be unsure themselves. That could have good effects beyond just letting people know what the heck the value—you know, how do you determine the value of something? To a great extent, it depends on what the dollar sign is behind it. And so we really need to know what those dollar signs look like.

Now, in terms of hospice, when my father died in 1974, hospice was only emerging. We were in a position to let him die at home—because, having been a physician for most of his 85 years, he did not want to die in a hospital. But I think an upshot of the hospice movement has been to help people see the dying process in a more comprehensive way. So it's not just, “I want to be kept at home,” but also, “I want to have a certain kind of environment. Even if I'm not at home, I want to have my family be able to come and see me whenever they want to, not when the institution says they can.” Things like, “I want my medication

to be carefully managed so that I can still interact. Or I want to manage my medication myself.”

The people who started the hospice movement understood all these things. And gradually, as hospice has grown in popularity, the larger culture has seen, “Oh, yeah, those are good things that we need to have when we're dying.” And it has spiritual aspects to it that it's really, really hard [to have] in a hospital. So I think that you get these little movements: “Show me what the bill is. Help me die the way I want to.” A few people would get that, and then the implications of that can spread to more and more people. They see how important these things are.

On healthcare and abortion rights positions seem to be ever more polarized and the idea of compromise discredited. Some recent state laws on abortion don't make exceptions for rape or incest and push the time limit to before many women even know they're pregnant, for example. With health insurance, some Democrats have embraced Medicare for All plans rather than “fixing” Obamacare—which is still being attacked by Republicans. In this environment, it's tempting to suspect that the kind of reasoning bioethics represents doesn't map very well onto our current political reality—or, at least, that the parties involved in making decisions aren't interested in putting it into practice. What's the response to that?

AG: Fortunately for the prospects of democracy in America, the positions you cite—ending abortion rights even in cases of rape or incest, abolishing private health insurance in order to provide Medicare for All—do not reflect anything close to majority public opinion in the US. Unfortunately, these positions—precisely because they are so simply and extremely expressed—gain disproportionate attention. And they do reflect the unproductive polarization of contemporary politics in America. Bioethics would be useless—indeed unethi-

“Bioethics would be useless—indeed unethical!—were its aim to mimic this political reality.”

cal!—were its aim to mimic this political reality. It would then become a megaphone for the powerful, the privileged, and the polarized extremes to the detriment of the common good.

Take the issue of abortion, which may be the single most divisive issue in our society, often viciously so. And grant that anything close to complete common ground is unavailable in the foreseeable future. It may seem futile to stand up, as we have, for the value of searching for more mutual respect and more common ground. The fact that a majority of Americans express quite nuanced positions even on abortion and the fact that these positions also change over time suggest quite the contrary. More mutual understanding, toleration, and respect for one another across our divides is both consummately practical and enormously valuable, even if we continue to disagree. Bioethical reasoning stands, among other things, for never ever taking toleration or civility or mutual respect across our many divides for granted. These are core social values of American democracy—they are the very linchpins of civilization—and they must be modeled, debated, and defended. Nowhere are reason and tolerance more important than in matters of life and liberty, birth and death.

JM: It's a good question. How do you break through the politics and the passions of the moment?

Within bioethics there have been some cases where that has happened. The Bioethics Commission that started under Carter and continued under Reagan produced some hugely influential documents, on gene splicing, for example. You could read it now and say, “Yeah, that's still the same standards and the same concerns.” There's one on informed consent. And on the cloning issue, the Obama, Bush, and Clinton administrations all agreed that you shouldn't do reproductive cloning. So you can break through. But it takes time. And the issue has to be ripe.

About abortion, I think we're all sort of at our wits' end. I think at the very least the life of the mother and incest and rape [ought to be considered]. And even incest and rape are kind of at hazard now, I know. But life of the mother's not. So there's still some inkling of hope. This is not exactly the topic, but some states are moving in a different direction. They're moving in the direction of more expansive Medicaid, like California's doing. But my view at least is it would be very unfortunate if we gave up trying to do this as one country.

You suggest that moving forward on universal healthcare in America will require a mobilization of public opinion, activism, and voting in support of it.

What would that look like, in your view?

AG: Americans consistently say that we want more bipartisanship in government, but just wishing for bipartisanship is naïve. We all need to focus our attention more on how to strengthen the responsibility of public officials for governing in office rather than on perpetually campaigning. To effect this change, we need to support commonsense reforms that incentivize elected officials to work together and to compromise across partisan divides.

A prime example that can move the needle is that the majority of Americans say they want to vote for public officials who support reforms that make health-care both more affordable and more accessible. However, a majority of Americans need to actually cast their votes on that basis.

Most importantly, we need not only to voice our opinions but to vote and to urge as many people as possible to vote. History shows us that major progress often

happens in fits and starts, taking far, far too much time—think of women's suffrage, civil rights, or social security—but when American citizens passionately voice and consistently vote their views on a subject of great importance to them, public policies tend to move in the direction of better serving the common good.

JM: We have to get over the rhetoric, like “socialized medicine” and so forth. We didn't go into this in the book, but that term actually came out of the World War I era. It started as a propaganda term because we wanted to distinguish ourselves from the German welfare system—obviously, pre-Nazi. So these terms are not helpful. And so that's just a kind of rhetorical problem and challenge.

The Romneycare example [in Massachusetts] is important to us. The notion that this can be done in a way that's compatible with the American system and that people recognized, in the case of Romneycare, that it ain't perfect the first year or the first two years, so you fix it. This is how society works. You have a problem with something you're doing, you don't say, “Well, obviously that's a bad idea. Let's walk away from that.” You say, “What are the specific areas where we can fix it?”

As to how that could happen and the kind of mobilization we talk about, if the quality problem gets worse, and fewer and fewer companies are providing traditional health insurance—if it happens, [the mobilization] happens from the ground up. People will look for candidates who have a better idea. But it is a problem that does require focus and not prejudice. Nobody, I think, is willing to lay odds on when this will happen. But one thing is the case. What we're doing now is just not sustainable. I'm 67. It's

hard for me to believe that in 20 years we'll still be where we are now. But I hope I'll be around to see something's better.

In talking about issues surrounding research on stem cells and the fate of embryos that took place during the Bush administration, you write that the chair of the president's bioethics council, Leon Kass, "was a trenchant critic of what he regarded as a tendency for both innovative biology and its progressive supporters to undermine moral traditions." In light of that and your own experiences, can you say anything about the role of politics in the issues taken up by different bioethics commissions and how those get discussed and resolved?

AG: When I led President Obama's bioethics commission, the commission both advocated and operated under the principle of deliberation, and not because I pushed that agenda. Commission member Daniel Sulmasy actually was a primary advocate for adding democratic deliberation as an essential principle to guide the commission's work. And the commission unanimously and enthusiastically practiced deliberation. That meant transparency and reason giving in trying to reach practical ethical conclusions to important issues. The successful proof of our deliberative approach was in the pudding. A great example was when then-HHS Secretary Kathleen Sebelius charged us with the question of whether it was ethical to test an anthrax vaccine on children. The vaccine had been used for decades in the military for adults, but there was no understanding of how to use it in children.

This was a case where the two sides seemed irreconcilably opposed to the positions of the other. Each thought that they held the moral high ground. One side essentially said, "We have to test this anthrax vaccine on children because if there is ever going to be an anthrax attack and we don't know how to administer this vaccine to children, children will die."

The other side more or less said, "It is ethically indefensible to test this anthrax vaccine on children because there is no anthrax attack and no way for us to meaningfully know the risk of one. We do know that if we test this vaccine on children, we are imposing risks on them to which they themselves cannot consent and from which they as individuals will not directly benefit."

How do you do you navigate this divide? What we did was to bring people together in open, transparent dialogue and deliberation in order to find the most ethical way forward.

After extensive conversation and analysis, we found that using an age de-escalation approach satisfied the moral imperatives and answered the moral objections of both parties. We described a progressive age de-escalation protocol: starting the study with 18-year old participants and then progressively testing the vaccine on younger and younger children, as our knowledge increased about the vaccine and its dose and its risks. This allowed there to be no more than minimal risk for each of the participants of this study. While minimal risk, this study provided precisely the kind of useful information that was needed should there ever be an attack. Both sides got what they wanted consistent with the most basic ethical principles—and above all the safety of individual children.

JM: I would say under Bush and Obama, and Clinton also, the commissions have reflected the temperaments of the president. Clinton and Obama tended to be very interested in particular policy issues in a very almost, I won't say "academic" because that sounds pejorative to me, but in a way that did not necessarily presuppose the same kinds of cultural issues that were presupposed by the Bush council. And the Bush council in fact did try to avoid writing documents that were too policy specific. They wanted to be educators and to raise sort of bigger philosophical questions that they thought got lost by technocrats.

The Clinton National Bioethics Advisory Commission would certainly have been regarded, I think, by many people on the Bush council as a very technocratic kind of operation. The Bush council thought that the role of a presidential commission should be to elevate the conversation.

I think that Amy [as chair of Obama's commission] had elements of both. For example, she had this very specific charge about vaccinating kids and the use of anthrax on kids.

But we also had the *Gray Matters* volumes [recommendations from Obama's bioethics commission on the implications of neuroscience research], which were big questions about science. And because the internet and social media had advanced so much, we also had more opportunity to do public education than the Bush council did because they were more limited in those days.

Commissions do tend to reflect the orientation of the presidents. And it is inevitable, I think, [since] they're set up to rise or fall with the president. Most countries that have bioethics commissions, or entities like this, are part of the system that simply continues, and a change in party doesn't necessarily change the personnel or the project.

That's the way our system is set up, though. And this has been true since the first Presidential Commissions. I mean, how you establish them and who's on them and what the goals are and what the president wants, that's very important. It's also possible for commissions to push back a bit on the White House. I've seen that happen from the inside. But for the most part they do reflect the orientation of the president.

Your discussion of new genetic treatments cites Jesse Gelsinger's death in a gene therapy trial at Penn in 1999 and the success of the CAR-T cell therapy pioneered by Carl June and his team ["The T-Cell Warriors," Mar|Apr 2015], which last year became the first such

therapy to gain FDA approval. Can you talk about the “perils and promise” of conducting this kind of research?

AG: The promise is obvious: diseases treated, conditions cured, and lives saved. Every time we see a picture of Emily Whitehead or any of the other people we have helped with CAR-T therapy, we see the astonishing success of this therapy and the great promise and hope that forms the very foundation of biomedical research and of academic medicine.

The perils are real and require acknowledgement, understanding, and attention. We have to understand the bold risks—both intellectual and to the brave people who volunteer for these studies—that pathbreaking research raises. It’s important that we obtain true informed consent from the patients who volunteer for these studies: that they fully understand the risks of their condition, the potential risks of an experimental treatment, but also the potential benefits to them and to others suffering from disease. We also have to build and manage complex interdisciplinary and interprofessional teams, negotiate complicated business and financial agreements and the conflicts that arise from them, and create and support advanced infrastructure. All these dimensions raise major ethical questions and quandaries, which means that ethical education is essential for our health professionals, researchers, and students—our nation’s future clinicians and researchers—who are doing this life-saving work. The promise of this work also critically depends on public support through institutions such as the NIH and the FDA, and private philanthropy as well.

JM: The death of one person in an important research project, the way our society is now, it’s not only a tragedy for that person and the family, but it’s a setback for the science. And we’ve learned, I think, to be much more cautious. I think the scientific community has taken this onboard. And yet the nature of research involving human

beings is a leap in the dark to some extent. If it wasn’t, you wouldn’t be doing it. This is something that won’t change until we can figure out how to improve computer models or animal models for certain disorders. Biology is really hard. You can write an app, many lines of code for an app, in an abstract environment. But biology doesn’t work that way.

So, it weighs heavily. And it is the case that some parts of the world are able to move a lot faster. But we can’t do that, and we shouldn’t do that, and we won’t do that. But it does present a competitive challenge, for sure.

The modern life sciences are extremely competitive, and they’re also not a zero-sum game. This is a tension, because what teams learn from each other is critically important. What one group is trying to do in Beijing or Shanghai or Fudan, when people at Penn or in Cambridge or in Palo Alto learn about it, it’s going to be hugely important for them to be able to work together.

But now we’re seeing a sort of isolationism creep in to the way science is done. And that will only slow down benefits to people. There have always been medical bio-security issues that we have to pay attention to. There are always national security issues. There are always intellectual property issues. But we’ve been managing them, I think, reasonably well. And now I fear we’re kind of spinning out of control. Time will tell.

China announced that genetic information in China is going to be restricted to Chinese investigators [under regulations that went into effect July 1, decreeing that international programs must include a Chinese collaborator, abide by Chinese law regarding use of materials, and share data and patents with Chinese institutes]. There’s a certain tit-for-tat going on at the level of science that most of us don’t pay attention to. But it’s eerily aligned with what’s going on in the trade wars. And I just can’t help but feel it’s not accidental.

Last question: Who do you see as the audience(s) for this book? What do you hope they gain from it?

AG: Andrea Mitchell wrote that this book should be “required reading for anyone with a heartbeat.” That may be a *bit* too much to expect, but I do think that everybody can benefit from reading our book. That’s because almost every day every one of our lives is affected by decisions about healthcare, public health, and mental health that are being made in our names, whether we are aware of those decisions or not. So we could be so much better off getting engaged in those decisions. Inevitable moral quandaries accompany tremendous medical progress. One way or another, sooner or later, these are issues that affect us all. We wanted to write a book that would educate all of us about the choices we face in this front. We hope it will help readers proactively think about their options well before they find themselves in an urgent situation involving important decisions about their own healthcare and the healthcare of a loved one.

JM: There have been some fabulous books in bioethics. No book, in the trade world, has been a big-picture look at the trajectory of bioethics and some of the big cases and how people like Amy and I would talk about them in class. With a little bit of theory, not too much. And links from the very beginning of the field to this day. I hope everybody reads it. But [the goal was] to create the basis of a public conversation about bioethics in a pretty comprehensive way. Especially as the science moves so quickly and as the cost of healthcare moves so quickly, to show that these are not simply parallel tracks; that there’s interaction between what the science has to offer and what people can actually get access to. And that’s the idea. Open a space for a public conversation, and one that is respectful to various sides, especially when you’re talking about issues like abortion and end-of-life care.