

Experts talk bioethics, healthcare in new book

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Amy Gutmann and Jonathan Moreno worked for several years together to pen the new book, named after a blues song, which hit the shelves at the end of August. Credit: University of Pennsylvania

The United States spends twice as much on health care per person than

any other affluent democracy. But that spending has not produced the results that might be expected, noted Penn President Amy Gutmann.

"Life expectancy has actually gone down in this country since 2015," said Gutmann, talking to a crowd at the Library of Congress National Book Festival, where she and co-author Jonathan Moreno launched [*Everybody Wants to Go to Heaven but Nobody Wants to Die*](#). "That is totally unacceptable."

"We have a [health care](#) system that's inefficient and inequitable," said Moreno. "That's the worst of both worlds."

Cue: An in-depth, engaging conversation about, in the author's words, "the inevitable moral choices that come with tremendous medical progress." Gutmann, a [political scientist](#), and Moreno, an expert on medical ethics, [health policy](#), and the history and philosophy of science, worked for several years together to pen the new book, which hit the shelves at the end of August.

The duo's hope? That their work boosts public conversation about health care, be it decisions about experimental treatments, increased public health funding, and end-of-life care, to encouraging people to become their own health advocates—even during a typical doctor's office visit.

Gutmann and Moreno, in the midst of a busy book-talk schedule (their next is on Thursday, Sept. 12, at the New York Public Library), sat down with Penn Today to discuss how they came together to write on the topic, why they're passionate about affordable, accessible health care for all, discussing controversial subjects in such a polarizing age, and much, much more.

As a political scientist and a historian, how did your

different approaches to the topic of bioethics help shape the book?

Amy Gutmann: Our work together on President Obama's Bioethics Commission laid the foundation for writing this book. We had the privilege of listening to so many moving stories of how health care and biomedical research impact people's lives. We also bring to this book a unique blend of backgrounds in history, culture, philosophy, political science, and bioethics—along with leadership of a large academic medical center and health system. In the book, we add our personal stories to those of our fellow citizens. It turns out that together we have not only studied but also witnessed and experienced major transformations of American health care and medical research. 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. Each year, there are numerous classes, programs, and events focused on the practice, finance, ethics, policy, and other aspects of medicine and health care—and Penn community engagement with these opportunities and issues continues to grow. Plus we really enjoyed co-authoring. The lively conversations we had no doubt also contributed to our being able to write a better book together than we could have apart.

With the breakneck speed at which health care and technology have advanced and continue advancing, where does bioethics come into play?

Jonathan Moreno: We have an ethical stake in everything that advances health care. Whether it be precious organs for transplant, disease-preventing vaccines, or expensive life-saving medical treatments, how do we ensure access and affordability to all who can benefit? In choosing IVF, in vitro fertilization, or surrogacy to conceive a child, in considering new therapies for cancer and other diseases, or in thinking

through end-of-life care, our lives and those of our loved ones often literally depend upon asking the right questions and answering them well. When health care is concerned, everybody is interested because nobody can possibly avoid confronting hard choices in our lives. And we have more choices than ever before in human history. As a consequence, many more people are intensely engaged—and rightly so, we believe—in confronting the many important bioethical questions in both our individual and our collective lives. Everybody can benefit from being so engaged, and that's why we wrote "Everybody Wants to Go to Heaven."

Should doctors be the ones to take the lead on this discussion?

AG: Each of us should lead some part of this discussion. Doctors and nurses—let's not forget how important nurses are—have leading roles. We can respect the agency and autonomy of patients and also enlist the expertise of doctors, nurses and other health care providers in helping to guide patients to excellent individualized decisions. Patients and the public benefit enormously when health care 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.

JM: A perfect example that's very much in the news is the debate over vaccinations, such as the polio and measles, mumps, and rubella vaccines, which are safe and have saved so many lives. While we have increased access to expert information since the time these vaccines were first approved, 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.

You write that we spend far more per capita on health care and medical science than any other country, yet we're not the world's healthiest. Why do you think that health care is falling behind in the U.S.?

AG: In some ways, our nation does have one of the best health care systems in the world. But—and it's the big 'but'—Americans don't even have universal, affordable access to basic health care. How can it be that insulin is not affordable or available to so many Americans who need it to live? Until we make universal access to basic health care a reality while controlling costs, we will continue to have among the lowest life expectancies and highest infant mortality rates of any industrialized nation. It turns out that increased access and affordability of health care actually can go together. We can make progress in ensuring access in health care and in advancing prevention of disease over treatment. When we do so—and we will do so as long as American citizens increasingly engage on this issue—health care will become more affordable, both individually and collectively. Americans don't want to dispense with all of the amazing things that are going very right in this country—and we don't need to. We can strengthen our commitment to innovation in effective biomedicine, which is saving lives, as long as we attend to equity in its cost and its distribution.

Do you believe affordable, accessible health care for everyone is possible in America?

JM: Absolutely. The history of major health care reform in this country suggests why. For many decades and at every major step along the way, including the path-breaking passage of Medicare in the 1960s, the

political fight for affordable, accessible health care has been polarizing. But Medicare is now wildly popular. Or consider fluoridation in the public water supply: It was once viewed with great suspicion, even as a Communist plot, but it's now largely taken for granted, having prevented millions of cavities in children and spared their parents and the public billions of dollars in expense. Embryonic stem cell research was once hugely controversial, but its life-saving potential has gained it significant bipartisan support over just the last several decades. The more citizens get engaged, the more they hold politicians' feet to the fire, the more optimistic we can be about the progress of affordable and accessible health care in our country, moving forward.

What is the public or political responsibility here?

AG: The responsibility of public officials is to govern in the public's interest, and not to be perpetually campaigning for office and doing next-to-nothing constructive once in office because they have jump-started their next campaign. We as citizens can support some commonsense reforms like an end to partisan gerrymandering of congressional districts, reforms that would positively incentivize elected officials to work together and to compromise across partisan divides.

Specifically with regard to driving affordable, accessible health care forward, when the majority of Americans vote for public officials who support constructive reform, it is more likely to happen. As citizens, we not only have the power to voice our opinions and vote but also to urge as many people as possible to vote. History shows us that major progress happens in fits and starts, taking far, far too much time—think of women's suffrage or civil rights or Medicare—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. There's no guarantee that Americans will always do the right thing, even after they've tried

everything else, as the oft-quoted maxim goes. But achieving affordable, accessible health care is a good bet if the vast majority of Americans mobilize public opinion and vote for it.

How is it possible to discuss these controversial topics in such a polarized age?

JM: When we look, we find many more ways to agree despite our ongoing disagreements. Making hospice care more accessible is one important example of a strongly shared priority among otherwise competing ethical perspectives. 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.

AG: Take the critically important goal of advancing health care reform and [health](#) equity. Many Americans today see these as big polarized and polarizing issues where consensus and compromise may be impossible to achieve. Working at a large, multifaceted, interdisciplinary university has taught us that we can work productively to find areas where we can agree and work from there. One practical maxim to live by as both a democratic citizen and a university citizen—'don't let the perfect become the enemy of the good'—at its root isn't a call to compromise our principles. Most fundamentally it's a call to make good on our principles in practice, by getting as many good things done as possible for all those whose lives and livelihoods depend on us. That's the ethical mission that gets both of us up every morning and that also guides our recommendations in this book.

Provided by University of Pennsylvania

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