THE ETHICS OF XENOTRANSPLANTATION

Also Inside:
Interview with Amy Gutmann
Chair of the Presidential Bioethics Commission

Placing the Patient at the Center of Care
Why did you decide to accept the position as Chair for the Presidential Commission for the Study of Bioethical Issues?

I was honored to have been asked by President Obama to chair this Commission. As a political philosopher and scholar of ethics, I believe that transparent, evidence-based deliberations with ample opportunity for public input can strengthen a healthy democracy. Chairing a group that is charged with advising the government on areas that affect so many people’s lives was a responsibility I was happy to accept. I also think that when the President asks, I should serve if I can.

You are praised for your strength as a communicator, how do you feel this will help you with the commission? What do you believe your strongest asset will be? What do you feel your role is?

I believe in promoting public discussion and improving public understanding of complex issues such as health care, science, and emerging technologies. In our current political climate, this sort of open and respectful discussion has become perilously rare.

The best any democracy can do when considering complicated and important issues is to encourage open, transparent discussion among a diverse group of experts and others with a stake in the outcome.

That’s what our Commission is striving to do — and I think we are succeeding.

How will your position as chair of this commission affect Penn? What influence does coming from Penn with the largest Bioethics Center in the country have on the commission and in return what impact do you think the Commission will have on the Center for Bioethics?

Many of the Commission’s members, including myself, are fortunate enough to serve at world-class universities with leading bioethics centers, and schools of medicine, arts and sciences, engineering, and law. Penn Law Professor Anita Allen also is a Commission member. These affiliations certainly benefit our work. Penn’s interdisciplinary Bioethics Center is a huge resource.

In our public meetings on synthetic biology, we’ve invited the perspectives of physicians, scientists, ethicists, policymakers, representatives of faith communities, and many others with expertise in these areas. We’ve included bioethicists and physicians from the most outstanding public and private universities in the nation, including Penn.

Your background lies heavily in philosophy and particularly in ethics as you served as the president of the American Society for Political and Legal Philosophy and as a founding member of the Association of Practical and Professional Ethics. From where did your interest in bioethics more specifically stem?

Bioethics is a thread that has been woven through my scholarly career, as I’ve written and taught extensively at the intersection of ethics and public policy. My first publication in the early 1980s in bioethics was a widely reprinted article on equal access to health care.

I am a fellow of the Hastings Center, perhaps the most prominent bioethics research institute in the United States, and earlier in my career I served as its Vice President. In the 1990s, Harvard political scientist Dennis Thompson...
and I co-authored a report, “Deliberative Democracy: The Case of Bioethics,” which explored how deliberative democracy can be applied to pressing matters in practical ethics, using bioethics as our paradigm case. I also taught a popular course on ethics and public policy for many years at Princeton, which launched many students into the theory and practice of bioethics.

Obama is said to have the “First Bioethics Presidency” which makes this the most critical commission yet, is that added pressure for you and the other members?

Well, there’s no question that President Obama is strongly committed to bioethics and that we are addressing issues that impact the lives of all Americans. As Commission members, we are focused on the socially and ethically responsible advancement of science, medicine and technology. We are also intent on ensuring that society benefits from new developments while appropriately managing potential risks. In addition to careful and thoughtful analysis of issues, we also have the opportunity to help President Obama strengthen science and healthcare policy by suggesting legal and policy actions to him and his advisors.

This commission was appointed primarily for the sake of giving a well-rounded view of bioethics to President Obama. Yet, bioethics is still an emerging field — does your commission have any plans on how to make it a better understood topic to Americans at large? How do you ensure that the public hears of the progress that you are making when you cannot directly facilitate or implement policy?

Like the science, medicine, and technology that are its subject matter, bioethics is moving faster today than ever before, and will continue to face the challenge of combining broad-based science and ethics education. As an example, consider synthetic biology, which is the issue we’ve been asked to study by President Obama. Synthetic biology is a relatively new field in itself, although it builds upon earlier breakthroughs in molecular biology and genetic engineering.

Our task is to help President Obama and the public better understand and help maximize the potentially great benefits from synthetic biology, most of which won’t even be seen until we get further down the road with the technology. We also need to determine how to minimize likely risks in light of what we now know. In addition, we need to describe our findings in a report that is publicly accessible.

Let me give you an example of how Bioethics Commissions can have a direct impact on public policy and on public consciousness of bioethical issues. In 1979, the Ethical Principles and Guidelines for the Protection of Human Subjects of Research — also known as the Belmont Report — created an important framework for the discussion of ethical treatment of clinical research subjects. The report also offered a common vocabulary for how we can responsibly treat human subjects in clinical research during a time when this field was expanding rapidly and in ways that were difficult to predict.

We face a similar challenge today in burgeoning fields such as synthetic biology. We need to articulate a framework for the ethical consideration of this and other emerging biotechnologies.

We’d like to advance the conversation around emerging biotechnological issues and create recommendations that can have a lasting impact on the whole field.

Previous commissions have been largely influenced by religion, do you think it is an important component of bioethics?

We have consulted widely regarding synthetic biology, including inviting representatives of different faith communities to our meetings. Given the important role that faith communities play in our society, their inclusion is vital in helping the Commission fulfill its charge of offering recommendations that ensure socially and ethically responsible advances in science, medicine, and technology.

Another thing that sets this commission apart from others is that there are fewer members. Is one reason for this that you would like the general public to be more involved in the happenings of the commission?

The more transparent and open our deliberations, and the more input we receive from the public, the better our recommendations will be. Democracy demands that we invite perspectives of all kinds — from both experts in the subject and interested citizens.

“As our nation invests in science and innovation and pursues advances in biomedical research and health care, it’s imperative that we do so in a responsible manner.”

-President Barack Obama

When people claim that the commission is too philosophical and not grounded enough in the reality of policy making and the fast pace at which technology moves, how do you respond?

It’s not only possible, it’s also desirable to be philosophical while still staying grounded in the practical realities. In fact, I’d argue you don’t want a commission that’s only able to do one or the other.

That said, our power ultimately lies in the reasonable-
ness of our recommendations. Then we have to leave it to those whom we advise. Our report soon will be out there in the public domain. We will have developed our recommendations by taking into account all the facts, the context, and the widest range of perspectives. This quality of the report will have value in itself. We will be giving the most practical advice possible, consistent with our mandate, to recommend ethically and socially responsible policies to the President.

Is it frustrating when technology moves quicker than deliberation and policy? You have six months to deliberate on synthetic biology but do you worry that a breakthrough before then could set a tone of precedent for the use of new technology?

The rapid pace of technological developments is one reason we are working to make recommendations that will have a lasting impact and that take lasting values such as justice, stewardship, and deliberation into consideration so that they may be applied no matter what issues emerge. Recent advances in synthetic biology notwithstanding, we will continue to face the challenge of evaluating emerging technologies, maximizing benefits while minimizing risks.

If our Commission can help establish a good framework to guide these evaluations, we will have helped strengthen both democratic deliberation and public policy in the long-term in this age of rapid technologic advancement. This is both an exciting—and a worthy—challenge to meet in six months time!

Bioethics is an expansive topic and yet at the moment you are focused on synthetic biology. We know that the President asked you to issue a report on this topic, and yet there are so many other items that need discussing as well. How do you pick and choose what is most important?

We will consider where we can provide the most “value added” in a timely fashion among the wide range of issues facing the country in science, technology, and healthcare.

The President has been clear in his first charge to the Commission: to provide practical, ethical advice on synthetic biology. Once we complete this report, we will take on another topic that can further our nation’s essential commitment to science, healthcare, and technology—and do so in a socially responsible and ethical way.

Bioethics Commission

Timeline of Bioethics Commissions. Adapted by Andrew Jakubowski.