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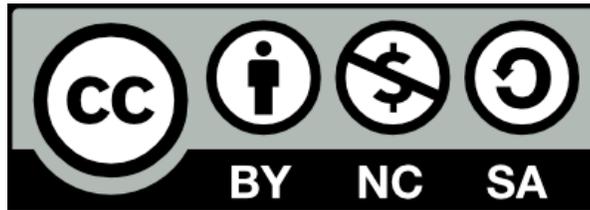
Anticipating Human Genetic Technology

Policy Possibilities for Public Discussion

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SEVEN CONTRASTING POLICY POSSIBILITIES

FOR PUBLIC DISCUSSION

Pages

Introduction: Human Genetic Technology as an Area of Public Policy Concern 2-7

Policies Focused on an Up or Down Appraisal of Genetic Technology..... 8-11

A. Don't Go—or Go Slow! Limit Human Genetic Technologies..... 8-9
These technologies are dangerous and potentially quite harmful to individuals and to our society. We should strictly limit or stop their development and future use.

B. Full Speed Ahead! Embrace Human Genetic Technologies..... 10-11
These technologies promise great benefits for everyone. We should embrace them and support their development and future use.

Policies Focused on Concerns about Control and Access..... 12-17

C. Let Each Decide—as Each Can Afford..... 12-13
Protect the rights of individuals to make their own decisions about human genetic technologies as they see fit—and as they can afford.

D. Let Each Decide—We're All in this Together..... 14-15
Balance individual and societal control of human genetic technologies by emphasizing mutual responsibility between the individual and society. Treat human genetic technologies as collective resources to which individuals should have fair and equitable access. Individuals should have the right to make their own personal choices and should be encouraged to make them in socially responsible ways.

E. Let the Community Decide for Everyone..... 16-17
Maximize the common benefit that might be gained from the use of human genetic technologies by centralizing control and treating them as shared community resources to be managed collectively and distributed fairly and equitably across society.

Other Policy Notions..... 18-20

F. Don't Let Anything Fall Through the Cracks—Seamless Oversight of All Technology... 18-19
Supervise human genetic technologies by establishing a seamless oversight framework for technical developments in general and biotechnology and human genetic technologies in particular.

G. Decide as We Go—Let Policy Evolve with Use..... 20
Allow public policy to emerge from the actual use of human genetic technologies, recognizing that there are limits on our predictive powers and that new technologies tend to shape culture as much as culture shapes them.

Human GENETIC TECHNOLOGY

AS AN AREA OF PUBLIC POLICY CONCERN

Imagine a world where, through the use of genetic technologies, you could be certain that your children would be born without disabilities? What if all children could be born without disabilities? What if they were required to be? Or what if these choices were only open to the wealthy? What if these choices meant you could reduce your child's risk of developing any of a number of diseases, say, Alzheimer's or Diabetes? Or what if you could lower your child's risk of developing behavioral or mental disorders? And, what if you could use these technologies to choose positive traits—not just to avoid diseases or disorders? Perhaps you could increase your child's chances of growing up to be tall, or athletic? What if you could choose that your child would have superior memory or mathematical abilities? Again, what if this could be expanded to all children—or was required to be? And again, what if these choices were only available to the wealthy?

What if you lived in a world where your entire personal genome could be put on a card as small and portable as a credit card? Genetic testing, combined with advances in the study of human genetics, might give you a fairly complete report about your likelihood of developing any number of physical or behavioral traits. For example, this information might indicate whether you, or your children, or your employees, will be likely to develop Diabetes, be physically agile, or prone to aggression. Would you want to know what your report said about you? Who else might want this information? How might this information impact your educational prospects, your job prospects, your marriage prospects, and your family relations? If we could know this kind of information, how might it affect the delivery of health care, the business of insurance, or the ways people have access to opportunities in our society?

Thirteen of your fellow citizens engaged in precisely these kinds of explorations in a series of discussions that extended over a period of roughly two years. Some of these citizens were experts in various aspects of human genetic technology and public policy; others had no special background on the topic. Together they developed contrasting

ways to look at human genetic technologies as an area of public policy concern and contrasting ways for public policy to respond to these concerns. They did not argue for any particular perspective or any particular approach to public policy. Instead, they aimed at developing contrasts in order to stimulate further democratic discussions. This document presents their thinking as an invitation to you as a democratic citizen to continue the discussion and to develop your own thinking about this complex area of public policy. To accept this invitation, simply think along with your fellow citizens about some of the following concerns.

What if, through the use of genetic technologies, all children could be born without disabilities? What if they were required to be? Or what if these choices were only open to the wealthy?

You might find your way into this exploration if you think of human genetic technologies in a very general way as any technical means to manipulate, intervene with, or examine human genetic material. These might be technologies of genetic testing, gene insertion or deletion, or "cloning" (transplanting genetic material whether to produce identical tissue or an identical organism). Try to imagine at time, perhaps in the not-too-distant future, when these technologies have been made to work far beyond their current state. Don't worry about trying to understand exactly how they work. Just imagine that they do work and that we are faced with a whole new world of choices. Using your imagination this way will help you to move beyond the technical details and focus instead on the long term political and social implications of these technologies.

Imagine a world where you're able to impact not just the future development of your children, but your own future. Suppose you'd be able to prevent the emergence of some illness, perhaps by inserting a gene or repairing a defective one. Or maybe you could choose to enhance your mental or physical abilities in some decisive way. Imagine you, or a loved-one, suffered a severed spinal cord in a car crash. Perhaps by using cloning technologies and some of your own genetic material, your physicians could stimulate the regrowth of your spinal cord, so you could walk again. Or perhaps your genetic material could be used to help give birth to a child who would be essentially your identical twin, a child with your identical genes.

When you think about this future world, try to think of some of the basic concerns that a democratic society might have to address. Again, don't worry about the details of how these technologies work. Imagine that we'll have to face many of the scenarios mentioned—and more. Now, ask yourself, what might be the public policy impact of being able to do these things? What are the social and political implications? What are the sorts of questions that we might have to answer as a democratic society, when it comes to crafting public policy to govern these technical capacities? As you think about the policy concerns surrounding human genetic technologies, you might think about them in five overlapping groups or as the five basic kinds of questions listed in the box below.

- **Questions about Basic Concepts**
- **Questions about Control or Authority**
- **Questions about Distribution or Access**
- **Questions about Human Identity and Diversity**
- **Questions about Science and Technology in a Democracy**

Questions about Basic Concepts. You might ask yourself, what are the big ideas or fundamental beliefs that might shape public policy for human genetic technologies? On the flip side, how might human genetic technologies affect these basic concepts or beliefs? You might want to explore the interactivity between these notions and human genetic technologies. You might think about the ways that these core beliefs might guide or determine the kinds of public policies we choose for human genetic technologies. And, you might think about how the very uses of these technologies might eventually change our thinking about some of these basic ideas. The following are some examples.

You might wonder how different notions of what it means to be human could lead to different public policy choices for human genetic technologies. And how might genetic technologies impact or change our understandings of what it means to be human? If we're able to make choices about our own biology instead of accepting certain traits as our inherited genetic fate, how might this change the way we think of our humanity, whether as individuals or as a society?

What about different notions of what it means to be "healthy" or "normal," or different notions of "disease" or "disability"? What if being "healthy" means more than not suffering from illness? How might these ideas change? What if traits we accept as a normal part of the variety of human existence, such as being bald, pudgy, short, or left-handed, are eventually seen as diseases or disorders subject to therapy or treatment? Who will decide what a disease is or what it means to be normal? In a world where "all the children are above average," what would it be like to be the child who was below average?

You might wonder about various beliefs or ideas that we often use to guide our thinking about human actions in a democratic society. Ideas such as being a person, being autonomous, or having personal liberty and individual rights. You might think about different ways to think about our obligations, duties, and respect for others. And you might think about such notions as justice, fairness, and equality. You might think about privacy,

QUESTIONS ABOUT HUMAN GENETIC TECHNOLOGY

and property, including intellectual property. You might wonder about the authority behind these ideas. Do they spring from our culture or religion—and how do we make sense of this in a culturally diverse society? Are these core ideas and beliefs dependent on private convictions or can they apply to everyone?

You might also wonder about the different goals that society might set for public policy for human genetic technologies. What if the goal were to maximize health? If so, do we mean for everyone, or only for those individuals who can afford it? What if the goal were to maximize individual liberty, or to maximize the greater good for society as a whole—in whatever way the society chooses?

Questions about Control or Authority.

You might ask yourself, who decides? Who might get to make the key decisions regarding the use and development of human genetic technologies? There is a whole group of concerns that relate to our power of choice, about who exercises control in human life, and about accountability for such decisions. You might feel that this is one of the major concerns that public policy will have to address. You might consider some of the following questions.

Who might get to decide what are the appropriate uses of human genetic technologies? And who might ultimately exert the greatest amount of control over such decisions? Might it be individuals and their families? Or would the government or various agencies acting on behalf of society or in the public interest control such decisions? Might it be the commercial interests of technology developers? What about health care professionals and scientific researchers? Or might it be the funding agents or the insurers (whether of health, life, disability, or liability)?

You might consider questions about the rights or liberties that might pertain to human genetic technologies. What limits might there be on the rights of individuals to make free choices regarding genetic technologies? Are there also rights of groups, for example, of certain populations or communities? And how might “free choices” relate to informed decision-making regarding such a complex topic as human genetics?

You might also wonder about the impact that genetic technologies might have on the very notion of being “free” to make one’s own choices. How might the choices of, say, a parent to select certain genetic traits for a child impinge on that child’s liberty? If others, say educators or employers, receive a report of your “genetic probabilities,” how might that impact your freedom? How far might we go in attempting to exert control over others’ choices? What about over our own biology? What limits, if any, might there be for extending human choices over own genetic makeup? And how responsible are you for your choices if your genetic makeup predisposes you to certain behaviors?

Who really counts when it comes to making public policy choices for human genetic technologies? The majority of society? What about minority populations?

You might also wonder about different ways to think of our obligations to one another. What might we owe to others, whether individually or as a group? Are these obligations to provide a needed service? Or are they obligations to stay out of the way and not to interfere? And who really counts when it comes to making public policy choices for human genetic technologies? Whose interests might we take into account? The majority of society? What about minority populations? Or groups of people who have been underserved by health services or underrepresented in policy decisions?

Questions about Distribution or Access.

You might ask yourself how these technologies might be made available and to whom. How will access to these technologies be distributed across society? You might wonder about how public policy might respond to concerns such as the following.

What are the core the values that might guide decisions about access to human genetic technologies? Might they be made available through free competition or through the economics of supply, demand, and the ability to pay? How might the use of genetic technologies impact such free competition and notions of fair competition? If you’re able to buy enhanced genetic traits for your kids, will

they be competing fairly on the playing field, in academics, or in the workplace? You might wonder about the ways that different levels of access to genetic technologies might impact individuals' ability to participate in society or to compete for opportunities.

You might wonder about what's really fair when it comes to distributing access to human genetic technologies. When you think about different ways to understand justice and equality, do these have to do with giving everyone the same amount of resources? Or do they mean providing different resources to meet different levels of need? Are these concerns more a matter of removing barriers or addressing the effects of past discrimination? Or are they more about enabling the fullest level of participation in society for each individual? You might also wonder whether the funding model we choose should be the deciding factor—or whether other values should be allowed to shape the funding decisions we make.

You might wonder about the way that different policy choices for the distribution of human genetic technologies might, in turn, impact the distribution of opportunities in society. Suppose others use information about your personal genetic makeup to decide what kinds of opportunities you might have in life? Your genetic information might lead others to make judgments, supported by good research or not, about your chances of developing certain traits or even skills. What if, given your genes, you are tracked into certain educational or employment tracks?

What if, given your genes, you are tracked into certain educational or employment tracks? What if you find certain opportunities closed off to you, simply due to your genetics rather than your performance?

What if you find certain opportunities closed off to you, simply due to your genetics rather than your performance? What if you could essentially buy better genetics, for yourself or your children? How might the management of educational or employment resources be impacted by access to such genetic information?

Questions about Human Identity and Diversity. You might wonder how human genetic technologies could affect our notions of human identity and diversity. What impact might there be on the ways we identify ourselves? How might it impact the ways we place ourselves into groups or trace our lines of connection to one another? You might feel that public policy will likely have to address some of these concerns.

What might be the connections between our various notions of what it means to be human and our policy choices regarding human genetic technology? You may wonder about the impact of these technologies on our individual or collective appreciations of what it means to live a genuinely human life. If we are able to insert genes from other species, or if we are able to select, for our children or ourselves, physical or behavioral traits that used to be left up to chance or nurturing, what impact might this have on our sense of human identity?

What might it mean to be “disabled” in a society where your parents could have chosen to make you otherwise?

You might wonder about the impact of these capacities on our sense of self, our self-identity. When we identify ourselves as healthy, normal, sick, or disabled, how might that change through certain policy choices about the use of genetic technologies? What might it mean to be “disabled” in a society where your parents could have chosen to make you otherwise? What about the impact of the ability of genetic technologies to help us identify specific individuals in cases involving missing persons, paternity, or criminal investigations? You might also wonder about the impact on our social identities, such how we think of our family or gender roles. How might the notion of parenthood change if your power of choice over your child's physical or behavioral traits is dramatically expanded? What about the impact on the ways certain communities or populations define themselves and their membership? Or how might others use genetic technologies to define groups from the outside, perhaps in ways that are discriminatory?

You might also wonder about the impact of human genetic technologies on various notions of human diversity. How might particular policy choices for

QUESTIONS ABOUT HUMAN GENETIC TECHNOLOGY

genetic technologies make us a less diverse society or a less diverse species? You might wonder about the kinds of diversity that could be relevant for public policy to consider.

- Biological or genetic diversity?
- Socio-cultural diversity?
- The diversity of intellectual or creative capacities?

And how might these forms of diversity be valued? How good are they—and what are they good for? What are the social implications if these technologies are used to make us increasingly more alike? Or what if they help to make us more diverse as a species?

Questions about Science and Technology in a Democracy. You might ask yourself about the ways that such complex topics of science and technology can enter the public arena in a democratic society. There are a group of concerns that relate both to the nature of being a multi-cultural democratic society and to the nature of science and of technology. You might feel that public policy will likely have to address some of the following.

What about the public policy implications of different ways of understanding technology in general, or human genetic technologies in particular? Suppose technologies always have unintended negative effects. How might public policy respond if technologies are always double-edged swords cutting two ways at once: unleashing negative effects that we can rarely predict along with the positive effects they are intended to create? How might public policy take into account the long-term effects or those that are difficult to quantify? You might also wonder whether there's something unique about human genetic technologies. Could they be in a class by themselves? Does the ability to change our genetics or to make informed judgments about our future development open a new door that hasn't been opened before? Or could it be that these technologies are really not so different from other technologies we already use? Might our policy choices consider only the immediate effects of genetic technology on individuals, or might it take into account the broader social and cultural effects as well?

You might wonder about whether or how the public will be informed about human genetic technologies. How might individuals make informed choices to use or avoid certain genetic technologies? And how might they, as democratic citizens, make informed policy choices about these technologies? Scientific knowledge is by nature a matter of probabilities. It tells us what is likely to be the case with varying degrees of certainty.

What are the social implications if these technologies are used to make us increasingly more alike? Or what if they help to make us more diverse as a species?

Science is also provisional. Its judgments change on the basis of new evidence and research. What challenges does this pose for public policy? Add on top of this the complexity of genetic interactions in particular.

Much of what we learn about our genes will have to do with thinking about probabilities—about how likely you are to develop this feature or that disease. And much of that will depend on how your genetics will interact with your environment and with your behavior. You might have certain tendencies based on your genes, but how might these be influenced by your diet and exercise? As you think about the complex inter-relations of “nature and nurture,” you might also call to mind the general tendency in popular media to oversimplify such issues. Consider the “gene of the day” news reports about the discovery of the gene for this or that complex trait. Such reports act as if it were always a matter of a single factor being the sole cause of a behavioral trait or disease. You also might think about the power of certain popular beliefs, such as the belief in genetic determinism, the idea that genes alone are sufficient to determine everything about us, even when the realities of genetic interactions with environment and behavior are much more complex.

When you think about the task of informing the public, you might wonder how this might happen. Who might be responsible for this? What might be the consequences of leaving it up to the private sector or of adopting a “consumer beware!” attitude? Or what if it is a public responsibility, where such efforts are carried out in the public interest? And what about the content of such education?

Would such education efforts focus solely on the relevant science? Or might they include reflection about broader social, cultural, moral, legal, and economic considerations? You may wonder, also, how these questions might be addressed in a society that speaks many languages and includes many diverse cultural traditions.

What might be the consequences of leaving it up to the private sector or of adopting a 'consumer beware!' attitude?

An Overview of the Policy Possibilities. On the following pages you'll find descriptions of seven contrasting policy possibilities. These possibilities respond in different ways to some of the questions and concerns about human genetic technologies raised above. Each possibility is intended to embody a distinct vision of a broad public policy response to human genetic technologies. Each description is intentionally short and sketched out only in broad strokes as a general way to frame public policy. As you read these, try to focus on the basic vision that each one presents, rather than getting bogged down in the details of how they might be implemented.

These policy possibilities are intended to be contrasting in the sense of exploring different, but not necessarily mutually exclusive, ways to approach human genetic technologies. You might think of ways that some of these could be combined with one another. Further, these policy possibilities are not intended to respond to every policy question raised above—just some of them. You may very well think of new possibilities or ways to expand upon certain aspects of these. The account you'll find here doesn't claim to be exhaustive or wholly novel. It simply offers you, as a democratic citizen, an opportunity to explore some distinct policy possibilities that might help you expand and clarify your own thinking about this complex area of social and political concern. It also offers you an opportunity to engage in discussion about these policy possibilities with your fellow democratic citizens.

The seven policy possibilities are presented on the following pages without regard to rank ordering.

Policies that Give an Up or Down Appraisal of Genetic Technologies - Possibilities A and B (Beginning on the next page)

What if you think that human genetic technologies are so fundamentally bad that they should be stopped? Or what if they're fundamentally good? Well, the following two policy possibilities offer contrasting responses to these basic questions. Your response may be rooted in your religious or cultural beliefs. It may spring from your moral or philosophical convictions. Whatever the roots of these convictions, you might feel that the role of public policy is basically to give a thumbs up or down to using these technologies at all.

DON'T GO—OR GO SLOW!

LIMIT HUMAN GENETIC TECHNOLOGIES

The continued development and use of human genetic technologies create unacceptable dangers—both to our moral and physical well-being. In response, this policy possibility aims at stopping, or at least limiting, their development and use.

Suppose you believe that human genetic technologies pose so many dangers to us, morally and/or physically, that it's better not to go down that path at all. Or you may believe that we should go slowly in pursuing new genetic technologies. The basic motto of this policy possibility is "Don't go—or go slow." If you are attracted to this possibility, you're likely interested in slowing or stopping the introduction of human genetic technologies. You might see this as a way to resist what is often called the "technological imperative," the belief that just because we can do something, we should. There's a saying, "To a person with a hammer, everything looks like a nail." You may believe that once we have technologies, it's often hard not to use them. So, this policy is a way to get rid of the hammer, or at least to make sure it's taken out less often.

You may be drawn to this possibility because it expresses your basic beliefs about what it means to live a human life. You may have concerns that people might go too far in using technology to change ourselves or our world. You might be worried about how poorly we can predict catastrophic side effects. There could be negative consequences of these technologies that we never saw coming, unintended consequences that could go on for generations. So you might be interested in setting clear limits to people's use of these technologies. As you think about the basic idea of this policy possibility, you might consider a couple of different ways it could be fleshed out.

On the one hand, you might think that the main point is to stop human genetic technologies, period. In that case, the policy may take shape as an unconditional ban—a "do not go" approach. Your main concern might be to set clear boundaries for the use of genetic technologies that simply should never be crossed. Your concerns may spring from your philosophical, moral, religious, or cultural convictions. For example, you may feel that any use of human

genetic technologies amounts to playing God—trying to control things we should leave up to a higher power. Or you might be motivated by the fear of opening a Pandora's Box—that using these technologies may unleash negative consequences that will quickly spiral out of control. This risk, and our inability to put the genie back the bottle, is so great that it's better not to allow their use at all. If you end up selecting this policy possibility, you are likely someone who is willing to accept things just as they are. This could mean doing without treatment for a loved-one if that treatment would involve genetic technologies. It could also mean that you'd support rolling back existing uses of these technologies.

On the other hand, you may not be prepared to go all the way for an absolute ban on human genetic technologies. You might rather have the policy take shape as a "go slow" approach. Your main concern might be human safety. But you might choose to make some room for risk analysis, rather than to adopt a wholesale ban on these technologies. Perhaps this could be expressed as a kind of "guilty unless proven innocent" approach. You might be interested in this approach if you want to err on the side of caution by restricting the use of human genetic technologies. At the same time, you may also realize that we can't totally stop them, especially since many are already in use. It may be impossible to turn back the clock and force people to stop using technologies that have already been adopted. It may be easier simply to slow any new developments. If you lean toward this approach, you may feel that the most important thing is to manage the negative consequences as best we can by moving slowly.

Considering Some Potential Consequences

One way to get a better understanding of what these policy possibilities might really mean is to discuss some of their potential consequences. The following are some considerations or questions that may help you do this. With each policy possibility, try to imagine what the world would be like, or how things might unfold, if this policy were in place. As you do this, it might help if you imagine different perspectives or different starting assumptions.

Administrative or Programmatic Consequences

- Consider how the policy might go about setting up administrative guidelines for implementing either a complete ban or more conditional limitations on human genetic technology.

Impact on Well-being, Health, and Healthcare Practices

- How might the policy impact the overall level of health of the population as a whole or of distinct classes of people, especially if genetic technologies are banned or limited?
- What are some possible consequences for the scientific and healthcare communities, whether at a national or international level, should a variety of human genetic technologies be limited or banned?
- Given that we humans can become preoccupied with things that are forbidden, what unintended consequences might emerge?

Technology Research and Development

- What are some possible consequences for technology research, technology development, and technology services, whether nationally or internationally?

Socio-Economic Effects

- What impact might the policy have on socio-economic inequalities?
- What impact might the policy have on economic growth, domestically and/or internationally?

Socio-Cultural Effects

- How might the policy impact human migration or people's decisions to move into or out of the country?
- What impact might the policy have on the way the society views human diversity or the way that it views those with disabilities?
- What impact might the policy have on the social attitudes or the moral character of the society as a whole? Consider whether or how the policy might lead to attitudes of acceptance or attitudes of fatalism. Consider how the policy might lead to a more caring society—or, contrarily, to an uncaring society.
- What impact might the policy have on the social roles of science and religion (or other cultural convictions)?

FULL SPEED AHEAD!

EMBRACE HUMAN GENETIC TECHNOLOGIES

We human beings are, by nature, tool-making and tool-using animals. Human genetic technologies are tools to exert control over our human biology and the natural world. This policy possibility aims at supporting their development and use as part of our inherent humanity.

Suppose you believe that using technology to change ourselves or to control our environment is a fundamental part of our human nature. It’s what we humans do. If so, you may feel that human genetic technologies are just another outgrowth of our basic nature. They represent powerful tools to change and possibly improve ourselves. In this respect, they are no more problematic than other technologies. They offer us new ways to extend our control over our own biology. Aspects of our human existence that used to be matters of destiny, things we just had to accept, could now become matters of choice. If this vision of human existence appeals to you might be attracted to this possibility. It aims at affirming the development and use of human genetic technologies as a basic part of our human nature. Human genetic technologies are “natural” for us, so we should embrace rather than resist their use.

Suppose this general approach meshes with your basic beliefs about what it means to be human: to be human is to be a tool-making, tool-using animal. If you look at it this way, you may be interested in taking an unconditional approach toward affirming human genetic technologies. You might be someone who’d affirm the technological imperative: the fact that we can do something means that we should. We really ought to pursue the development and use of human genetic technologies, because to do otherwise would be a violation of our basic nature. We really should use human genetic technologies to try to improve ourselves individually and/or as a species, because such efforts are what make us truly human. This kind of a blanket approval might appeal to you if you are motivated by core philosophical, moral, or religious convictions about the meaning of being human as a technological and self-transforming animal. If you affirm this unconditional approach, you might also believe that society has an obligation to support the development and use of human genetic technologies.

Or you may be interested in a more cautious approach to affirming human genetic technologies. You may still be motivated by similar beliefs about being human as a technological animal. But you might want to make room for some cost-benefit analyses when weighing potential uses of human genetic technologies. Instead of an unconditional “yes” to such technology, you might think of this as an “innocent until proven guilty” approach. In general, we as a society should craft public policy to affirm the use of human genetic technologies unless there is a balance of evidence against particular uses. If the potential harms outweigh the potential benefits, then we may have to disallow some human genetic technologies. You may lean toward this conditional approach if you like the idea of affirming technology as something natural, but are less concerned with uniformity and more concerned with preserving the ability to adjust policy decisions on a case-by-case basis.

The fact that we can do something means that we should. We ought to pursue the development and use of human genetic technologies, because to do otherwise would be a violation of our basic nature. We really should use human genetic technologies to try to improve ourselves individually and/or as a species, because such efforts are what make us truly human.

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider how the policy might go about implementing either an unconditional affirmation or a more conditional affirmation of human genetic technology.
- Consider the kinds of mechanisms for public education and public input needed to sustain this policy over time.

Impact on Well-being, Health, and Healthcare Practices

- Consider how the policy might lead to a greater risk of negative, or even catastrophic health effects. What about its effects on the process of human evolution? What if people choose non-adaptive traits, traits that make it more difficult for them, or their offspring, to survive or live healthy lives?
- How might the policy impact the overall level of health of the population as a whole or of distinct classes of people?
- How might the policy impact the overall practice of healthcare?

Technology Research and Development

- How might the policy impact technology research and development? How might it affect the relation between technical experts and the general population?

Socio-Economic Effects

- What impact might the policy have on economic development, both domestically and internationally?
- Consider how the policy might lead to expanding levels of socio-economic inequalities with increased discrimination (in areas like employment and education)? Alternatively, consider how it might lead to socio-economic equality across society if it affirms genetic technology as a public good.
- Consider how it might lead to increased international cooperation, or, in contrast, increasing international conflict.

Socio-Cultural Effects

- Consider how the policy might lead to a cultural attitude that overemphasizes the value of technology in general, and human genetic technologies in particular. Contrarily, consider how it might lead to a cultural backlash against technology.
- Consider how it might lead to a cultural mindset overemphasizing the role of genetic factors in human health and development. Or, contrarily, consider how it could lead to a more balanced understanding of gene-environment interactions.
- Consider how the policy could foster a mindset of conformism and a preoccupation with being a “perfect” human. Or, contrarily, consider how it might lead to a backlash against such conformism.

POLICIES FOCUSED ON CONTROL & ACCESS - Possibilities C, D, & E. What if the questions about human genetic technologies at the top of your mind are “who gets to choose?” and “who will have access to them?” The following three policy possibilities respond to these kinds of questions. Each explores a different way of determining who might get access to these technologies. Each one describes a different way that control might be exerted over the uses of these technologies.

LET EACH DECIDE—AS EACH CAN AFFORD

This policy possibility aims at protecting the rights of individuals or their proxies to make decisions about the use and development of human genetic technologies as they see fit—and as they can afford. These technologies are commodities to be woven into the exchange of goods and services in a free market, an environment that should be largely free from social or governmental intervention.

Suppose you believe that individuals should be free to choose to use whatever genetic technologies they can afford. You might be someone who strongly respects the pursuit of self-interest. People should largely get to do what they want, as long they aren’t going to hurt others. That’s the basic idea of this policy possibility, which could be summed up as “you get what you pay for.” Or, “you can do it, as long as you can afford it.” Individualism, the ability to express yourself as an individual without interference from others, might be a core value to you. And you may see human genetic technologies as a significant way to express your individuality. These technologies offer a powerful way expand your power of choice over your own biology or that of your children. Things that used to be seen as a matter of your genetic destiny may now be seen as a matter of choice. You might also think of these technologies as opening up an individualized approach to health care, through the knowledge of each person’s genetic information.

By this line of thinking, you might treat human genetic technologies as commodities that we could buy freely – like any other good or service. Human genetic information and material could also be thought of as goods for sale. These technologies would be developed in order to make a profit. The free pursuit of profit could work to foster technological advances. And, those who would like to make use of these advances should, of course, have to pay for them. You might feel that you should have the liberty to use what you can afford unless your choice might put someone else in danger. If you do hurt someone, or you’re worried that you

might be hurt by the choices of others, this policy possibility makes room for a third-party to mediate your dispute. Perhaps there could be some minimal oversight to keep this market flowing. Maybe in some cases you could see the government stepping in to say that your choice of a certain genetic technology poses too many dangers for others. But overall you’re likely to be comfortable with a “buyer beware” attitude.

People should largely get to do what they want, as long they aren’t going to hurt others. That’s the basic idea of this policy possibility, which could be summed up as “you get what you pay for.” Or, “you can do it, as long as you can afford it.”

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider how the policy could lead to the implementation of a minimal level (or safety-net) of access to some human genetic technologies using an economic rationale. Or, consider how it might lead to the implementation of some protections against genetic discrimination and/or against genetic privacy violations.

Impact on Well-being, Health, and Healthcare Practices

- How might the policy affect the overall level of health of the population as a whole or of distinct classes of people?
- Try to imagine the impact on the cost of the healthcare system. How might this impact affect the practice of healthcare or healthcare financing? Consider how it might lead to the disappearance of low-cost healthcare providers. Or, contrarily, how it might lead to the emergence of discount healthcare providers.

Technology Research and Development

- Consider how the policy might lead to an increase in technology innovation and quicker, more efficient, technology development.
- Consider how it might lead to a decrease in socially useful forms of technology development and an increase in human subject violations. Contrarily, consider how it might lead to technology that is more clearly responsive to genuine human needs.
- Consider how it might lead to the emergence of low-cost genetic technology developers, or development that focuses on niche markets. Contrarily, consider how it might lead to technologies solely focused on either the mass market or the upscale market.
- Consider how it might lead to the commercializing of personal genetic information and/or genetic material, whether for individuals who want to market their own “property” or for others who might want to exploit them commercially.

Socio-Economic Effects

- What might be the impact on the different economic classes within society, and on the wealth of the society as a whole? Consider whether the policy might lead to a situation where class distinctions would eventually become biological distinctions.
- Consider how the policy might lead to increasing usage of genetic information in determining access to opportunities, such as employment and education. Might this lead to a more cost-efficient way of matching people to the best opportunities, or to rampant discrimination?
- Consider how the policy could allow commercial interests to set specific public policies for human genetic technologies. Or, conversely, consider how it might decrease favor-seeking behavior by commercial interests and decrease public corruption, since there will be little or no centralized public role in setting policy directions.

Socio-Cultural Effects

- What might be the impact on the social mindset? Consider how the policy might lead to increasing social harmony—a kind of “live and let live mentality” that values individual diversity. Alternatively, consider how it may lead to social fragmentation and an attitude of constant competition, resentment and social unrest. How might it affect the moral sensitivity of society?
- Consider how the policy might lead to an eventual decrease of individual liberties, whether due to the power of commercial agents to overwhelm individuals’ personal control or through the power of conformism in a consumer culture.

LET EACH DECIDE—WE’RE ALL IN THIS TOGETHER

This policy possibility aims at balancing individual and social control over the development and use of human genetic technologies. Society is responsible to individuals by making sure that everyone has an equal opportunity to make informed choices about whether or how to use these technologies. In turn, individuals’ choices should be responsive to the good of society as a whole.

Suppose you believe that every individual should be equally free to make his or her own choices about human genetic technologies. You may see human genetic technologies as a significant way to express your individuality. These technologies offer a powerful way to expand your power of choice over your own biology. Things that used to be seen as a matter of your genetic destiny may now be seen as a matter of choice. You might also think of these technologies as opening up an individualized approach to health care through the knowledge of each person’s genetic information. Yet you might also wonder whether an individual is really free to exercise such choice if financial barriers stand in the way. Further, you might be concerned about the ways that unequal access to human genetic technologies could rapidly widen the gap between the rich and the poor. At the same time, you might believe that an individual’s choices should be socially responsible.

If this line of thinking appeals to you, you might appreciate the way this policy possibility aims at a balance of mutual responsibility between the individual and society. You might think of it as expressing the way the society and the individual can take care of each other. Society is responsible to its members by removing financial barriers to access to human genetic technologies. This means treating these technologies as community resources and providing support for informed decision-making. All community members should have fair and equitable access to them. Individuals should have the right to make up their own mind about whether to use them or not, regardless of their financial status. At the same time, the policy holds that individuals are responsible for making choices that take into account the greater good of the society.

Suppose you are someone who is motivated to preserve individual choice and to lessen social inequalities. This policy addresses those concerns by putting collective resources in the hands of individuals, so that each person can make up his or her own mind about them. Individuals would have access to choices about human genetic technologies within the context of universal access to affordable health care. Such universal access will address many of the concerns about genetic discrimination, and about inequalities in opportunities, that lie at the heart of this policy area. This policy would also encourage the pursuit of public-private partnerships in the research and development of human genetic technologies.

You might feel that society has the obligation to educate individuals so they can make informed decisions both about the immediate health-effects of these technologies, and also about their broader social effects. This policy possibility entails some mechanism for public education and discussion. This would empower informed decision-making and facilitate individuals’ input into the direction of the policy (in terms of deciding how best to use such community resources). In all, this policy possibility functions by pooling community resources to enable diverse individual choices.

This possibility aims at a balance of mutual responsibility between the individual and society. Individuals should have the right to make up their own mind about whether to use genetic technologies or not. And individuals are responsible for making choices that take into account the greater good of society.

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider how the policy might lead to various implementation strategies for a universal healthcare system that would encompass affordable access to human genetic technologies.
- Consider the kind of education efforts that would be required to sustain citizens' ability to participate in informed and socially responsible decision-making about human genetic technologies.
- Consider how the policy might develop means of stabilizing itself against the ebb and flow of partisan electoral politics.

Impact on Well-being, Health, and Healthcare Practices

- How might the policy impact the overall level of health of the population as a whole or of distinct classes of people?
- Consider how the policy might change society's approach to healthcare or its understanding of "health." Consider how it might lead to a preventive and wellness focus for healthcare. Or consider how it might lead to society intruding on the healthcare choices of individuals.

Technology Research and Development

- Consider how the policy might lead to a greater focus on socially useful technology development. Or consider how it might lead to increased cronyism to take advantage of any aspect of public funding for technology development. Further, consider how it might lead to a black market for banned technologies or the migration of technology development abroad.

Socio-Economic Effects

- How might the removal of profit incentives for sellers and financial barriers to consumers affect the cost-effectiveness and sustainability of the system of distributing needed genetic technology services (and healthcare services in general)? In the short-term? In the long-term?
- What might be the impact on people's employment decisions and their sense of economic freedom, such as to pursue alternative kinds of employment?
- How might the policy impact the cost of the healthcare system overall?
- How might the policy impact socio-economic inequalities in the society as a whole?
- How might the policy impact the distribution of common resources?

Socio-Cultural Effects

- Consider how the policy might lead to a mindset that places humanitarian concerns ahead of economic ones.
- How might the policy impact individuals' sense of autonomy, of being in control of one's own life choices?
- How might it impact individuals' sense of social responsibility or the overall sense of social solidarity in the society? Consider how it might lead to greater social unity or, contrarily, to greater social fragmentation.
- How might the policy impact the society's affirmation of diversity or its attitude of conformism?
- What implications does the policy have for creating "buy-in" from culturally and economically diverse populations?

LET THE COMMUNITY DECIDE FOR EVERYONE

This policy aims at maximizing the common benefit that might be gained from the use of human genetic technologies by treating them as shared community resources to be managed collectively and to be distributed fairly and equitably across society. Just think of the race to put a man on the moon: as a society, we do better meeting our national goals when we pool our resources and coordinate our efforts.

Suppose you believe that human genetic technologies represent powerful tools to enhance public health and the overall level of well-being across society. You might also believe that the best way to maximize the benefit of these technologies for the greater good of society would be to centralize their control and to treat them as shared community resources. You might also be concerned about social inequalities and how these might expand if only the wealthy had access to human genetic technologies. You might reason that the best way to maximize the benefit of these technologies for the society as a whole would be to make sure they are distributed fairly and equitably, without regard to an individual's financial status. They should be made available and used in a way that would most benefit society as a whole. This policy possibility embodies these beliefs.

As you think about this policy, you might reason that some kind of public body would be needed to make decisions about the possible uses of human genetic technologies. The policy entails the social regulation of these technologies, so there would have to be some mechanism for reaching collective agreements about the appropriate uses and purposes of genetic technologies. This social regulation would address the range of concerns associated with genetic technologies, whether concerning their immediate health-effects or long-term social effects, with an eye toward maximizing the common good.

Suppose you are concerned about the ways that unequal access to human genetic technologies might greatly enhance socio-economic inequalities. The policy responds by providing universal access to approved genetic technologies, regardless of an individual's ability to pay. Genetic technology services would be provided, for example, as part of a universal health care system that aims at elevating

the population's overall health and at enhancing the distribution of health throughout the population. This means there would be public control of human genetic technologies within a publicly run, or not-for-profit, health care system.

As you think about this policy, you might consider the value of harnessing the power of many minds working together, especially as the policy pools such collaborative efforts for research and development. Research and development of human genetic technologies would be carried out in the context of a national technology policy. The goal of such a policy would be to foster the development of those forms of technical innovation and development that are most socially useful.

There would have to be some mechanism for reaching collective agreements about the appropriate uses and purposes of genetic technologies.

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider how the policy could lead to various approaches to a public system of universal healthcare as different ways to exert collective control over human genetic technologies, such as: a government-run system with public employees, or a publicly-funded system with private providers (as part of a non-profit system).
- What efforts for informed public decision-making and informed citizen participation might be required to enable the long-term success of the policy?
- Consider how the policy might lead to society placing limitations on access to technologies that cannot be made available to everyone.
- Consider how the policy might make effort for minority and individual protections to prevent the good of the many from harming the few. Alternatively, consider the possible consequences if the policy were to be implemented in a way that focused solely on maximizing the good of the majority without any protections for minorities or dissenting individuals.

Impact on Well-being, Health, and Healthcare Practices

- How might the policy impact the overall level of health of the population as a whole or of distinct classes of people?
- Consider how the policy might change society's approach to healthcare or its understanding of "health." Consider how it might lead to a more preventive and wellness focus for healthcare. Consider how it might lead to society intruding on the healthcare choices of individuals.

Technology Research and Development

- What impact might the policy have on technical innovation and/or the development of socially useful genetic technologies?
- How might the policy impact whether the practices of science and technology are socially responsive?
- What impact might the policy have on the economics of the research and development of human genetic technologies?

Socio-Economic Effects

- What might be the economic impact of the policy on society in general or on the healthcare system or commercial technology developers in particular?
- Consider how the policy might affect socio-economic inequalities in the society or people's sense of economic freedom.
- Consider how it might impact the ways that opportunities are allocated or managed, such as in employment or education.
- Consider how the policy might impact the relations within the whole society of various sub-populations (such as racial or ethnic groups), including how the majority population might treat such groups (or might treat those who dissent from the majority consensus).

Socio-Cultural Effects

- Consider how the policy might affect the society's sense of social cohesion or social fragmentation.
- Consider how it might affect favor-seeking behavior or public corruption.
- Consider how it might impact citizens' attitudes about their role in civic life. What kind of citizenry might the policy produce?

OTHER POLICY NOTIONS - Possibilities F & G. You might think of other concerns that are not addressed by any of the above policy possibilities. There are other ways for public policy to approach human genetic technologies. The following are two such possibilities. You might think of ways to incorporate them as part of other policy possibilities, or you might think of them as interesting stand-alone alternatives.

DON'T LET ANYTHING FALL THROUGH THE CRACKS

SEAMLESS OVERSIGHT OF ALL TECHNOLOGY

This policy possibility aims at the comprehensive supervision of human genetic technologies by establishing a seamless oversight framework for technology in general and biotechnology and human genetic technologies in particular. The chief concern is to better anticipate and manage the short and long-term effects of any new technologies.

Suppose you are primarily concerned about the potential short and long-term effects of human genetic technologies and how these effects may be very hard to foresee. You might reason that this seems to be the case with all technologies; they always affect society in unpredictable ways. Some consequences might seem quite positive, others quite negative. You may feel that public policy should be to offer supervision of such technology in the public interest. You might also be concerned about the tendency of such oversight to focus on the immediate or most easily measurable effects. You might look to public policy to provide a way to review and manage the immediate and long-term effects of these technologies.

This policy possibility entails establishing a seamless oversight framework for all technology. You might favor this approach if you think that human genetic technologies are not really all that different from other technologies in terms of their potential consequences. All technologies raise questions about their immediate and long-term impacts. These may be impacts on individuals or on society as a whole. This policy sets out an overarching framework to anticipate those potential impacts on a wide swath of human life.

Suppose you are also concerned that some technologies could fall through the cracks of various oversight mechanisms or jurisdictions. You might be concerned that lapses could occur along the way from the development lab to the consumer or patient. This policy intends to create a framework for technology supervision that horizontally integrates all areas of technology. It is also integrated

vertically from the development lab to the consumer or patient. This means the policy would integrate and coordinate governmental and non-governmental oversight. Some technology supervision would be done by public or governmental bodies, and some by the self-governance of professional societies, trade groups, or other organizations. But all these supervisory bodies would be tightly interwoven and coordinated, with fewer chances for technology concerns to fall through the cracks.

You might also be concerned with monitoring and managing the social impacts of technology. If so, you might favor expanding our supervision beyond a narrow focus on individual safety. This policy envisions oversight that would include a consideration of the broader social, moral, legal, cultural, and economic impacts of technology. Such supervision would ask not only “is it safe for the people who use it,” but also, “how might its use affect the kinds of opportunities people have to participate in society?” or “if this technology is widely used, how might it change our society?” Human safety and the physical environment would still be guiding concerns, but so would the impact on our social world, such as how the technology might affect what it means to be a free or equal member of society. This policy would require people with various forms of expertise to craft and staff the oversight framework. It would entail the participation of individuals with backgrounds not only in the natural sciences, but also in the social sciences, law, and the humanities.

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider the institutional mechanisms and processes that might be developed for addressing potential economic, ethical, legal, and social issues across diverse communities in a multicultural society. Similarly, what kind of mechanisms might be put in place for expanding oversight of human subject protections?
- Consider how the policy might develop mechanisms for community consultations for diverse communities within a multicultural society to support the above efforts.
- Consider how the policy might take different approaches to developing a centralized oversight body for science and technology, or to developing different oversight bodies at various levels of governmental or non-governmental organizations.
- Consider how the policy might be implemented to focus on the seamless oversight of genetic technologies alone.

Impact on Well-being, Health, and Healthcare Practices

- How might the policy impact the overall level of health of the population as a whole or of distinct classes of people?
- Consider how the policy might change society's approach to healthcare.

Technology Research and Development

- Consider how the policy might affect the influence of politics, or other ideological or partisan debates, on science and technology.
- Consider how the policy might impact technological innovation or the pace of new discoveries. Also, how might the pace of such discoveries affect the capacities of oversight envisioned by this policy?
- What implications might the policy have in regard to intellectual property?

Socio-Economic Effects

- What might be the overall economic effects of the policy?

Socio-Cultural Effects

- Consider the impact of the policy on public awareness of the social implications of various technologies, or on the public's ability to deliberate about the potential risks and benefits of various technologies.
- What kind of social mindset is likely to emerge from this policy?

DECIDE AS WE GO—LET POLICY EVOLVE WITH USE

This policy possibility intends to allow the specific contours of policy to emerge from the actual uses of human genetic technologies. Given our limited powers of prediction, we should let our policies toward human genetic technology adapt and evolve as we accumulate more experience and evidence about the specific benefits and challenges that lie ahead.

Suppose you feel that technologies in general always end up shaping society just as much, or even more, than we ever can hope to tame technology to our purposes. You may believe that public policy does a better job adapting to changing realities than it ever does trying to predict how things will develop in the future. This policy possibility responds by allowing the contours of public policy for human genetic technologies to emerge in response to the actual uses of these technologies. Instead of trying to foresee the potential fallout of these technologies, this approach would allow policy to evolve as adaptations to situations that occur through the various uses of human genetic technologies.

Suppose you're someone who wants to make sure that public policy decisions are based on accumulated experience or testable research—rather than on conjecture or speculation about what might happen in the future. You might also feel that our predictive powers are not that reliable. We might, for example, shut down whole avenues of potentially beneficial technology development simply due to fearful imaginings of opening a Pandora's Box. Or we might lose our ability to adapt to changing conditions if we simply rely on proactive generalizations about technology. In contrast, this approach allows policy to change as our knowledge-base regarding human genetic technologies expands.

Considering Some Potential Consequences

Administrative or Programmatic Consequences

- Consider how the policy might develop a variety of diverse responses as it reacts to a range of consequences from specific uses of human genetic technologies (such as those noted below).

Impact on Well-Being, Health, and Healthcare Practices

- Consider how the inherent influences of some genetic technologies might impact the practice of healthcare, models of healthcare financing, or other kinds of risk insurance.

Technology Research and Development

- Consider how the policy might affect the respective roles of science and of ethics (or other social or cultural concerns) in shaping the specific governance of genetic technologies.
- Consider how the policy might impact the creativity of the scientific and technical communities.
- Consider how the policy might impact the development of socially-useful technologies, or of technologies focused on the needs of minority populations or those of lower socio-economic status.

Socio-Economic Effects

- Consider how the policy might impact regional, demographic, and socio-economic inequalities in access to human genetic technologies.
- Consider how the policy might affect socio-economic inequalities in the society as a whole.

Socio-Cultural Effects

- What kind of social mindset might emerge from this policy?

An Open Invitation to Further Discussion & Interactivity

We hope that you will use this report to carry forward the discussion begun by our project panels.

In addition to this report, we have developed a citizen discussion process that may be helpful for groups or discussion facilitators interested in discussing the ideas presented in this or in any of our other Citizen Discussion reports or in discussing other matters of public interest. To assist in the planning and conduct of these discussions, we have developed certain corresponding facilitation and discussion guidebooks. These discussion materials, as well copies of this report and our other Citizen Discussion reports, may be downloaded from our website (listed below). And, you can obtain additional printed copies of any of our publications (at no cost) by sending us a request that briefly indicates their intended use. See the contact information listed below.

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Finally, and perhaps most importantly, we invite you to enter into discussion with us and welcome your comments, ideas, and other feedback about this Citizen Discussion report, its possibilities, any of our publications, or our discussion processes. Simply contact us via any of the addresses listed below:

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Thank you! We look forward to the interactivity.

