

GENERATIONS
AHEAD

Responsible Uses of Human Biotechnologies in the Twenty-First Century

The decoding and sequencing of human DNA has paved the way for exciting scientific discoveries, a multibillion-dollar biotechnology industry, and a hopeful array of new developments in medicine and health. As a country dedicated to democratic processes, the people of the United States need to determine which values and policies should shape our uses of human biotechnologies and genomic medicine. Policies in this area can and will impact the most intimate aspects of American life and challenge deeply held moral and ethical values. This mandates that consideration and decision-making about the responsible uses of these technologies be **transparent, trust-worthy and participatory**. The American public needs and deserves a seat at this public policy table.

Scientists are unraveling the mysteries of the human genome and experts are translating those discoveries into pioneering treatments and therapies in ways that can remake social and cultural understandings of humanity. As genes claimed to predict obesity, athleticism and infidelity are theorized and decoded through direct-to-consumer genetic tests, people's understanding of who they are and what they control in their lives is shifting. As gestational surrogates and sperm and egg donors are sometimes embraced in families, definitions of family are expanding. And as ancestry tests reveal genetic and geographical lineages, ethnic, racial and community identities can be socially altered.

For all their groundbreaking benefits, some genetic technologies come with life-changing risks. Focusing on the genetic contributions to health can shift attention towards predetermined genetic causes of disease and illness and away from social and environmental causes of health disparities. While DNA forensic databases are important crime-solving tools, they can also lead to an additional bias against communities of color in the criminal justice system. Assisted reproductive technologies now allow people to have biological children who previously could not, yet they increasingly offer options about what *types* of children people can have. Genetic testing can give expectant parents critical information, but has also led to a dwindling population of people with Down syndrome and other disabilities, threatening the respect and valuing of people with disabilities.

Genetic science and technologies can, and in some cases already are reshaping how people understand themselves, how they define family, and who they consider as a part of their community. To ensure that the uses of these technologies do not lead to division and dystopia, collectively we need to decide how to use them in such a way that our social understandings of family, community and selves affirm a shared humanity and a democratic future.

Now is the time to develop a broad and deep dialogue with the American public to determine when and how we should use these new scientific discoveries, and in some cases, *if* we should use them at all. Transparency, trust and diverse community participation are critical to this project: technologies that can lead to scientific racism and eugenics, the exploitation of vulnerable women, the commodification of children, genetic determinism, and the elimination of people with specific types of disabilities can not be left to experts or commercial interests in small meetings behind closed doors. Full disclosure and extensive public engagement is a must. Trust, confidence and commitment to new policies will develop only through inclusion and transparency.

Solution: A Seat at the Table and a Stake in the Outcomes for the American Public

- I. **Community Representation:** Ensure broad community representation on any President's Council or National Advisory group on bioethics and human biotechnologies. Half of any of



these groups should be experts – professionals in science, industry, medicine and bioethics – and the other half should be people from community-based, religious and public interest groups, representing human rights, racial justice, women’s health, disability rights, civil rights and LGBTQ rights. There should be notable representation of historically disenfranchised groups – people with disabilities, people of color, women, children, parents, economically vulnerable people, and lesbian, gay, bisexual and transgender people. Diverse and minority perspectives are essential in these advisory groups, as these policies and practices can and do impact different constituencies in markedly different ways.

- II. **Public Consultation:** In addition to the standard Public Notice and Comment process, a Public Consultation will lead to more active involvement of interest groups, a two-way dialogue between the government and the public, increased transparency and trust, and improved agreement and political support for any new regulations. Public Consultation allows for the inclusion of multiple perspectives and alternatives, helps identify unintended effects to diverse constituencies, and provides transparent ways to balance opposing interests. A Public Consultation on Bioethics and Human Genetics could include a series of town-hall meetings in partnership with community groups, citizen and expert advisory groups, webinars, webcasts, YouTube videos, and websites. This Public Consultation process could be modeled after the Transition Process, with robust and unprecedented public participation and multiple venues for dialogue using innovative communications technology.
- III. **Impact Assessments:** While scientific research and discovery should not be curtailed, responsible oversight and regulation of the uses of human biotechnologies must include an assessment of impact. Intention and impact can often diverge, and risky uses in the short and long term need to be evaluated based on the effect of the use, not simply the intention. Impact Assessments will allow the government to identify unintended detrimental “downstream” impacts on individuals and communities, consider alternative means of achieving broad-based health and public benefits, and facilitate an on-going dialogue with the public about maximizing beneficial effects and minimizing harms, particularly to minority constituencies. Requiring an Impact Assessments Protocol at all levels of public policy making on human biotechnologies will systematically expand the public debate and require on-going consultation with stakeholders, both expert and community-based.

The three tools of Community Representation, Public Consultations and Impact Assessments will ensure that intent and impact in the uses of genetic technologies are aligned, that multiple stakeholders are invited to participate in meaningful ways at every stage, and that the government is engaged in an on-going dialogue with important interest groups regarding critical understandings of humanity, equity, fairness and inclusion.

While President-elect Barack Obama has taken a much-needed stance in defense of the integrity and importance of science, the voices, perspectives and values of the American public must be included upstream in any decision-making about the uses of genetic technologies to affirm American values of fairness, inclusion and equity. While the highest purpose of science is the search for knowledge, the highest purpose of government is to protect and defend the common good, in this case, our shared humanity. This goal may be achieved through broad-based community participation in generating policies on the responsible uses of genetic technologies. The processes outlined here can insure that both of these noble goals—the search for knowledge and the defense of our shared humanity—can inform and reinforce each other, embodying American democratic ideals in scientific practice.

Generations Ahead works with organizations around the country to humanize tomorrow’s genetic technologies through stakeholder dialogue today. We bring diverse communities together to expand the public debate and promote policies on genetic technologies that protect human rights and affirm our shared humanity. By building the capacity of more than 100 civil society organizations to develop more informed positions, we have increased the number of perspective and voices involved in national discussions about human genetic technologies.

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