

Reston Citizen Democracy Meetup  
Anticipating Human Genetic Technology  
Facilitator: Jeff Prudhomme  
Session 1, 9-28-09

## Overview

This was Session One of a projected series of four Meetup discussions of the Interactivity Foundation's citizen discussion report on *Anticipating Human Genetic Technology*. This discussion focused on the first part of the report, exploring the different kinds of policy concerns that might arise with the advance of human genetic technologies. The report served as a sort of guidepost for the group to delve into various topics. The discussion was not limited to what was in the report. There were six participants and the discussion was facilitated by Jeff Prudhomme.

The discussion focused on exploring the area of concern, discussing some of the many different questions or concerns about the social and political implications of human genetic technologies. The discussion started by assuming a time in the future when a range of these technologies would be functional and relatively safe. These technologies would enable us to know far more about each individual's genetic predispositions (physical and behavioral), and allow us to intervene with or manipulate our genetic material (to affect physical or behavioral traits, to treat diseases, or to regenerate tissue or even clone another human).

The following notes are intended to capture some of the themes that came up in the discussion. These are presented as possible concerns or questions that might come up regarding human genetic technologies. These are not intended to represent the particular beliefs or opinions of any of the participants.

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## Summary Notes

### Ethical concerns

- How can we avoid unnecessary human suffering? What if genetic technologies cause others to suffer harms?
  - For this discussion we're assuming that we've figured out a way to make these technologies work in a way that is relatively safe. But they will always be very complex, with complex interactions of genes and environment, so there will always be uncertainty about risk assessment.
  - Do we have a right to take these risks (of causing further suffering by using some form of genetic technology) with ourselves?
  - Do we have a right to take these risks with others, such as our minor children? What if genetic interventions affect future generations of our families, so that our children and grandchildren might suffer from our decisions to use genetic technologies?
- There's a concern or obligation to alleviate human suffering, to help people be healthy. This could mean providing needed genetic technology services (to fix things that are fixable)

- Withholding treatment also causes suffering. There's an ethical obligation to make available genetic therapies available to anyone who needs them in order to restore their health.
- What ethical obligations are there to aid the poor, or those who are most vulnerable in society, perhaps by making genetic technologies available when they can prevent or treat diseases?
- What rights should people have in regard to human genetic technologies?
  - Is there a right to a certain level of treatment or care, if it is a matter of restoring a baseline of health?
- As a society, our sphere of ethical concern may be expanding over time. We tend to expand the realm of beings that should be protected (expanding notions of “who counts” for ethical consideration), so we might have a greater weight to avoiding harms to non-human beings and not just harms to humans
- There are concerns about the ethics of “engineering” our offspring by using genetic technologies
  - It seems ethical to use such technologies (e.g. genetic testing) to avoid conveying a genetically-linked disorder to your children
  - It seems ethically troubling or outright wrong to use genetic technologies to enhance your children beyond a basic level of health
- There are concerns about fairness and fair play in society
  - How fair is it that wealthy parents might “buy” better genes for their kids, thus assuring them greater opportunities to succeed in our society?
  - Wealthy parents can already buy better opportunities for their kids—so how different is this?
  - Athletes already use performance-enhancing drugs—what will happen to fair competition if they turn to genetic technologies to enhance their performance?
- There are line-drawing concerns: where do we draw the line between the individual and the society?
  - When is the use of genetic technology purely a personal concern—and when does it become society's concern? When is society justified in stepping in on my decisions (or my families)?
  - Society has an interest in avoiding bad diseases and an interest in maintaining a certain baseline level of health in the public at large, but does it have an interest in improving people's abilities beyond that baseline?

### **Notions of health and healthcare**

- Some might think of health as a certain baseline, a minimal level to aim at for individuals or the population as a whole
- Some might think of health as wellness, which could mean encouraging people to get in the best shape they can be, to maximize their health and to prevent illness to begin with

- Some might think of health as avoiding illness, avoiding disease and suffering
- Some might think of health as enhancing ourselves beyond previous limits, reaching for perfection
- Health standards change over time. What is “normal” is changing: what people expect from health today is not what they did years ago (we expect more)
- Health standards are shaped by what insurers/health plans will cover (widespread view that dental and vision care are not part of “health”)
- Healthcare might get more individualized with advances in knowledge about human genetics and about the interactions of medicines with certain genes (a certain medication might not work for you given your genes)
- Healthcare might take on a more preventive focus
- What are the implications of “regenerative” medicine—enabling people to re-grow tissue (say, by using cloning technology) that has been damaged by disease or injury?
- We have a tendency to increasingly “pathologize” conditions that used to be seen as “normal” (or stuff you put up with as a normal part of life). More and more conditions get re-described as “diseases” that could/should be treated. This trend will expand with human genetic technologies, since we’ll be able to make more choices about aspects of human life that used to be accepted as unchangeable.

### **Concerns about control or decision-making**

- Who should get to define “health” or what is “normal”? Each individual? Social consensus? Whoever is paying?
- Should the public, or the government, make decisions for the good of the whole population? (Using the analogy of vaccination for public health: if you want to go to public school, you have to get vaccinated)
- What decision-making role might insurers play? Technology developers? Parents? Government?
- Should parents’ ability to make genetic choices for their kids be limited in any way? What about the potential impacts on future generations?

### **Access or distribution concerns**

- Who is going to have access to our personal genetic information (or genetic material)? What are the implications of trying to control this information?
  - What if there is a national database for all this genetic information?
  - How might people use or misuse this information?

- People who can “buy better genes” for their kids are going to have an unfair advantage over the rest of us. It will give them access to greater opportunities to get ahead in our society.
- What if there’s a general social interest in improving the overall health of the general population by using genetic technologies? What if there’s a general interest in improving other attributes (such as intelligence)?
- What might be the differences if we take a for-profit approach to genetic technologies vs. a public-interest or non-profit approach?
- Should money drive all the key decisions about developing or using genetic technologies?
- Who would/should protect the public interest, or the interest of patients or vulnerable populations? What about people who are poor or who fall through the cracks?
- What role should the public play in supporting the development of genetic technologies?
- Small groups that are very vocal might shape policy for genetic technologies simply because they are outspoken—not because they represent popular opinion
- How should we measure the costs of decisions to use or not use genetic technologies (or to make them available to broad populations)? Genetic technologies will largely focus on future effects (such as preventing a certain disease from occurring), so there will be costs for not using them as well as for using them.
- What are the implications if the development of genetic technologies depends on small populations (rather than the usual approach of looking for big block busters)? If some genetic technology is only relevant to a small slice of the population, then will commercial technology developers put any money into it?

### **Population concerns**

- What are the implications for the population as a whole if people start gravitating toward engineering their children to have similar attributes? (Most will want their kids to be tall and smart, etc.) What are the consequences if we all are too much alike?
- Society has an interest in public health, in the overall health of the whole population. What might be the implications of this public health focus for making genetic technologies more widely available?
- How might genetic technologies impact the course of human evolution?
- What are the implications in a global context, especially in terms of immigration, of developing human genetic technologies and/or making them widely available?
  - The population won’t stay static—whatever policy is adopted will likely change the population (e.g. might make more immigrants want to come here, which could make the policy unsustainable)

**Public education concerns**

- How are people going to get the information they'll need to make informed choices about human genetic technologies? How can the public be educated about such complicated topics?
- How will the demise of science journalism impact the public's knowledge about human genetic technologies?
- What are the implications if this educational task is taken on with a for-profit approach vs. a non-profit/public-interest approach?

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