

Reston Citizen Democracy Meetup  
Anticipating Human Genetic Technology  
Facilitator: Jeff Prudhomme  
Session 2, 10-12-09

## Overview

This was session two of a projected series of four small group discussions of the Interactivity Foundation's citizen discussion report on *Anticipating Human Genetic Technology*. This discussion focused on 2 of the 7 policy possibilities included in the report: Possibility C ("Let Each Decide –As Each Can Afford") and Possibility D ("Let Each Decide—We're All in This Together"). These are 2 of the possibilities that focus on how we might address concerns about control and distribution (there is one other of these that we did not yet get to discuss). In other words, these respond to concerns about who is going to get to make the key decisions about the use and development of these technologies—and how are people going to get access to them?

There were 4 participants: Allen, Carol, Raul, and Jeff (the facilitator).

The discussion focused on exploring each possibility as if it were the way that our society decided to deal with human genetic technologies (imagining that these technologies, such as genetic testing, gene insertion or deletion, or other manipulations of genetic material, such as therapeutic or reproductive cloning, were all functional well beyond their current state and more or less safe).

---

## Summary Notes

### Policy C: "Let Each Decide –As Each Can Afford"

- Concerns about the free market as a driver for genetic technology development
  - A free market would mean more freedom for individuals--that people could do what they want with human genetic technologies
    - Eventually market forces might bring prices down, so that more people could afford genetic technology services (just as other new technologies gradually drop in price)
    - There are cases where commercial interests have funded important breakthroughs (Pasteur)
  - Market-driven research and genetic technology development might be problematic
    - Science can't be forced to match the market: people might want what is not scientifically/technically possible
    - There is often no direct link from scientific breakthroughs to economic success (the market doesn't always reward the developers of important breakthroughs)
    - The market will likely fail to develop technologies that are beneficial to the common good but that are not lucrative

- The range or field of genetic technologies will shrink to cover only those areas that promise short-term commercial viability
  - Might the government have to backstop those areas of genetic technology development that are in the interest of public health but where there is little prospect of profitability?
  - Might the government offer liability protection for public-interest genetic technology applications?
  - But this policy foresees no real public or governmental role in managing human genetic technologies
- Slow or less effective genetic technology development
    - Genetic technology development would be unfocused, since there's no effective way to aggregate consumer demand
      - You need economic clout to get what you want; isolated consumers can't do this on their own
      - This could work if people formed co-operatives, like a public utility to meet shared needs in a commercial setting
      - Commercial development might work if there is some capacity for setting up a monopoly (like a public utility) to give free rein to technology development
      - Maybe individuals could select areas of technology development where they'd like voluntary tax contributions to go (like volunteering a portion of your taxes to go to federal elections)—but again, this policy sees no role for public support of genetic technology use or development
    - The free-market or commercial approach would likely encourage more lawsuits regarding liability, and this will slow genetic technology development
    - There will be no common public underlying infrastructure of basic scientific research (as exists today), and this will slow genetic technology development
      - There will be no public role in funding basic research or setting up the infrastructure to support basic research
      - Most technical and scientific breakthroughs have emerged through some form of public support
  - Global Situation: a brain-drain from the US
    - There would likely be a brain-drain as our best and brightest in genetic technology research and development would migrate to those countries that offered the public support infrastructure for research and development
      - The US would fall behind countries like China and India, no longer being a global leader in science and technology
  - Intellectual property concerns
    - This policy would likely encourage individuals to try to control their own genetic information or genetic material as an important piece of intellectual property and possible wealth-generator
      - People might want to copyright their kid's genome as soon as the kid is born

- People might want to start licensing their own genetics, if developers might make important discoveries based on them
- This raises concerns about why people should be rewarded for something they didn't work to acquire (or maybe just compensate when there is pain and suffering for the test subjects?)
- Commercial entities will seek to profit, however, from test subjects, so why shouldn't those test subjects be compensated?
- All of this is a consequence of seeing every transaction as a commercial transaction (according to the gist of this policy)
- Does a population/group/or leadership have a right to negotiate property rights over genetic information for that population (e.g. Iceland selling genetic info of all Icelanders to a private technology developer for commercial development)
  - What would be the appropriate pay-off to individuals?
- Moral concerns
  - What should be the line of social morality regarding what you can sell and what you can't?
  - How would this policy relate to the moral demand to help reduce human suffering regardless of concerns about profitability or commercial viability
  - This basically seems like an unfair policy
  - Are there any moral criteria, beyond individual desires and economics, for deciding what genetic technologies will be developed or how they will be used? This policy seems to have no moral limits on people's behavior
  - This policy encourages us to see every interaction as a commercial transaction, so it is likely to inhibit our moral sensibilities and discourage transactions based on "sharing" or the common good

#### Policy D: "Let Each Decide—We're All In This Together"

- Public health interests
  - This policy seems more likely to have needed genetic technologies go to those who actually need them to address human suffering; it conveys a public responsibility to help those in need
  - It puts public resources into genetic technology research and development to help those most in need
  - But this policy allows individuals to opt-out
    - What if that hurts the community (like people refusing to get vaccinated)?
    - Who should be liable if others are hurt by these opt-out decisions? Need some mechanism to limit liability for others when individuals opt-out
  - Could some people be required to have genetic testing (e.g. like model of drug-testing certain government workers?)
    - This seems to embody the notion that the good of the whole outweighs to good of the individual
    - But this policy aims at striking a balance of the community and the individual
- Concerns about the conflict of choosers

- The policy emphasizes individual choice, but what happens when individuals or groups choose opposing things?
  - What if parents want to engineer a peer group for their kids, e.g. by using genetic testing as part of screening for a school? (This isn't so very different from restrictive schools that only wanted kids from certain established families)
  - Employers and insurers are likely to want individuals' genetic information to help make actuarial calculations about risks and probabilities
    - What will happen when some individuals refuse to disclose this information? Might they lose a job opportunity—especially if most everyone else in the pool will disclose this genetic information?
    - Opting out doesn't free you from negative consequences (people might assume you are hiding something bad)
  - When deciding to opt out of/undergo genetic testing,
    - There could be things that you can do something about
    - There could be things that you can't do anything about
    - There might be a stigma associated with these, so you won't want others to know
    - There could still be a public value to this information, for public health research
    - Genetic testing could be done in an anonymous way to support genomic research, so that the information could help others and contribute to the public good
- Concerns about genetic discrimination
  - It seems like there would have to be some form of protection against genetic discrimination for this policy to work (protect against employment or insurance discrimination based on your genetic information, if you opt to have genetic testing done)
    - This would encourage use of genetic testing and disclosure of genetic information that could be useful to others (if we protect the tested individual from adverse social effects)
    - We need to make sure that individuals are not punished for “pro-social” acts (for the public good), otherwise they are less likely to take these actions
    - There could be cases where certain genetic information could be job-related, and so it could be used in making employment decisions
- Concerns about genetic screening
  - Current concerns over pre-existing conditions will combine with genetic testing revealing future possible conditions
  - What if school children are required to have full biological workup (including genetic makeup) before starting school? As schools screen for certain backgrounds—maybe they'll screen for certain genetic attributes
  - Prospective spouses might want prenuptial genetic screening
- Technology development
  - Genetic technology research and development would be enhanced by this policy, since there would be public money to support research and development

[end]