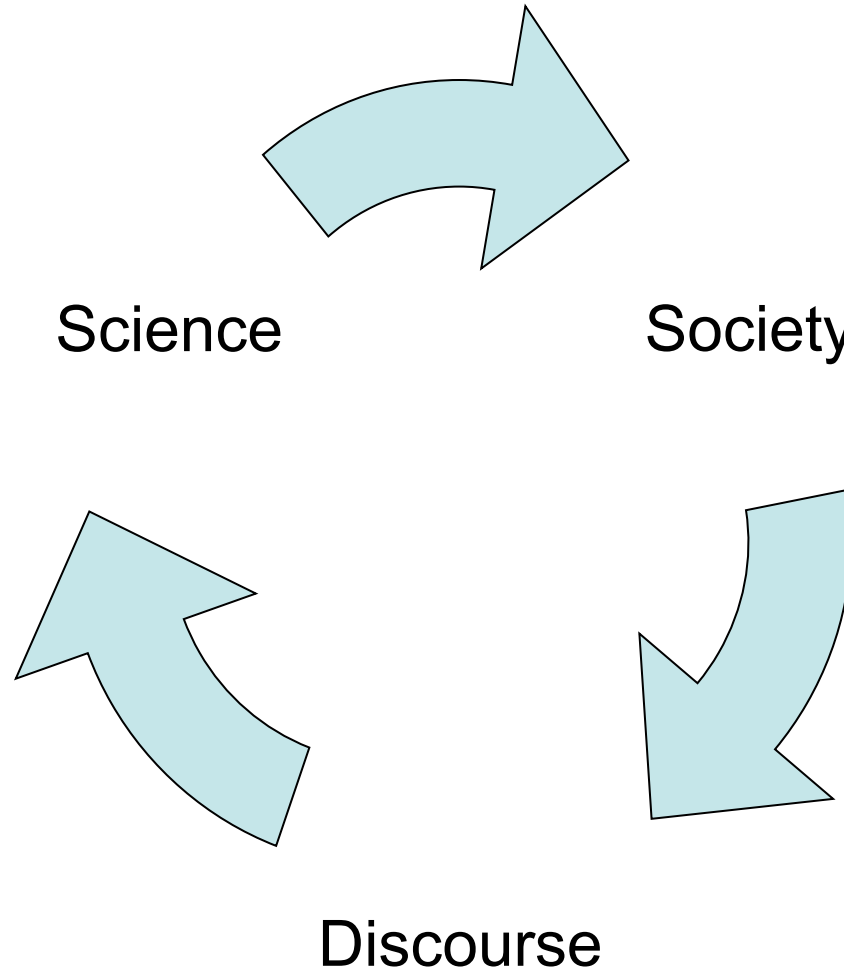


Personal Genomics and the Social Sciences and Humanities

Personal genomics is not just a physical and life sciences issue: it is a political, economic, and social issue

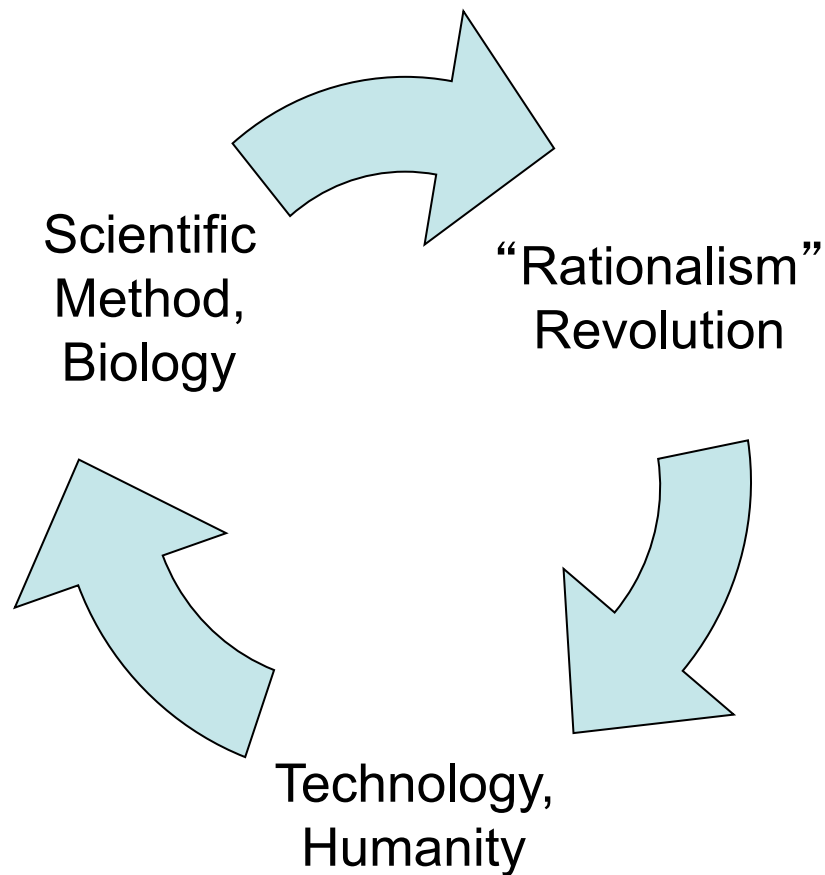
We need to be aware of how we are embedded in a larger social discourse on molecular biology and genetics.

Society and Prediction: *Zeitgeist*

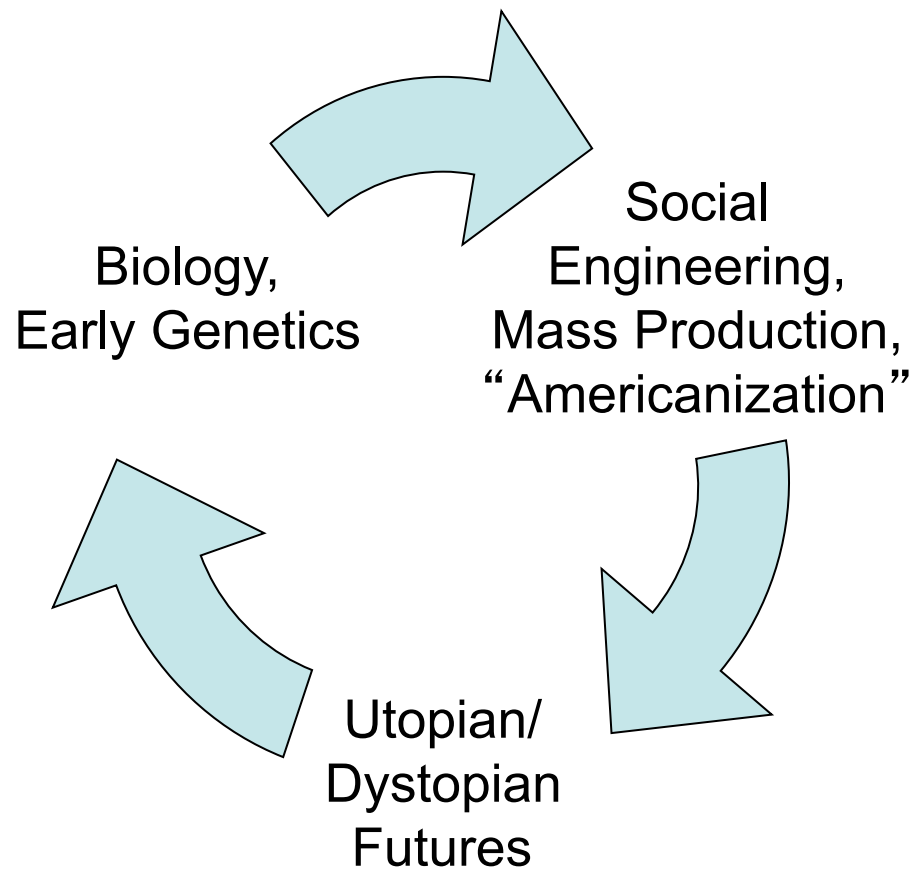


Society and Prediction:

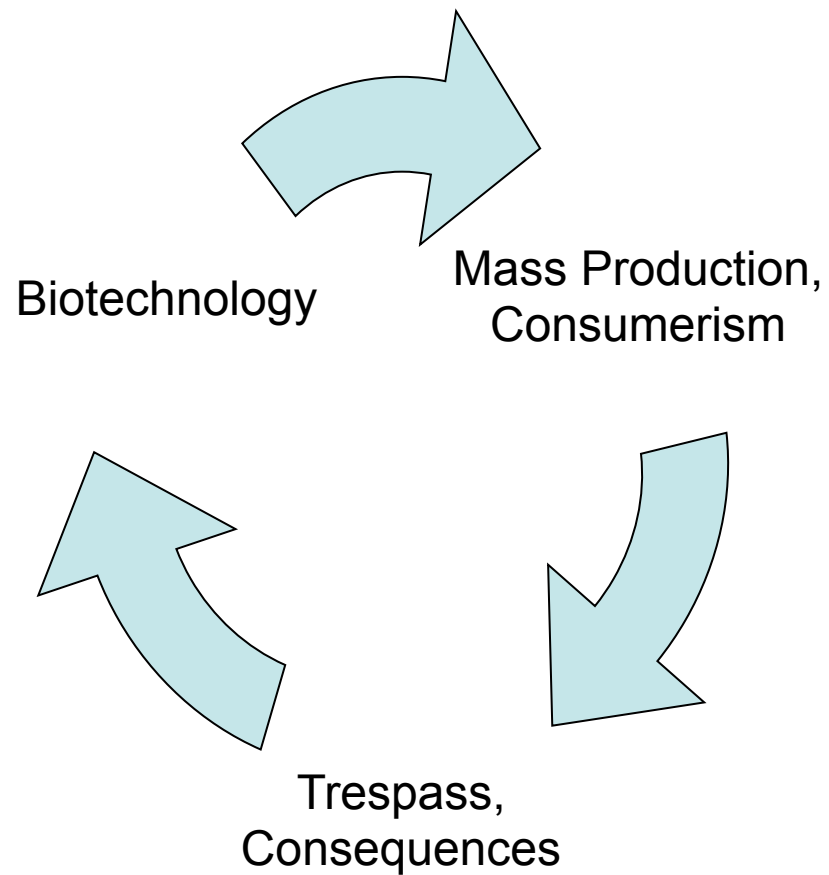
Frankenstein: or, The Modern Prometheus (1818)



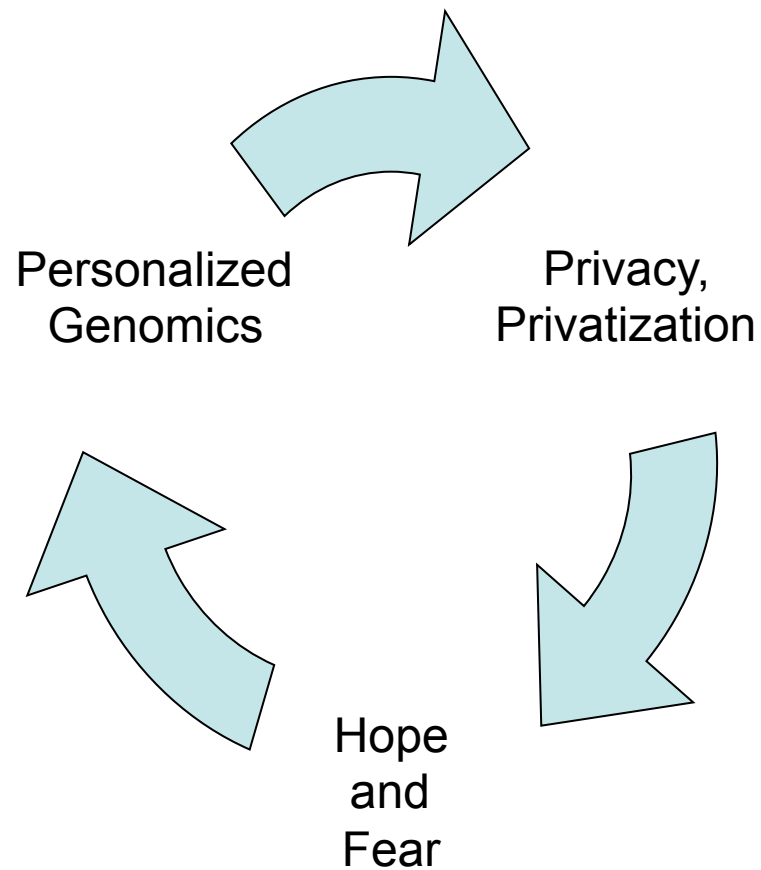
Society and Prediction: *Brave New World (1932)*



Society and Prediction: *Jurassic Park* (1990)



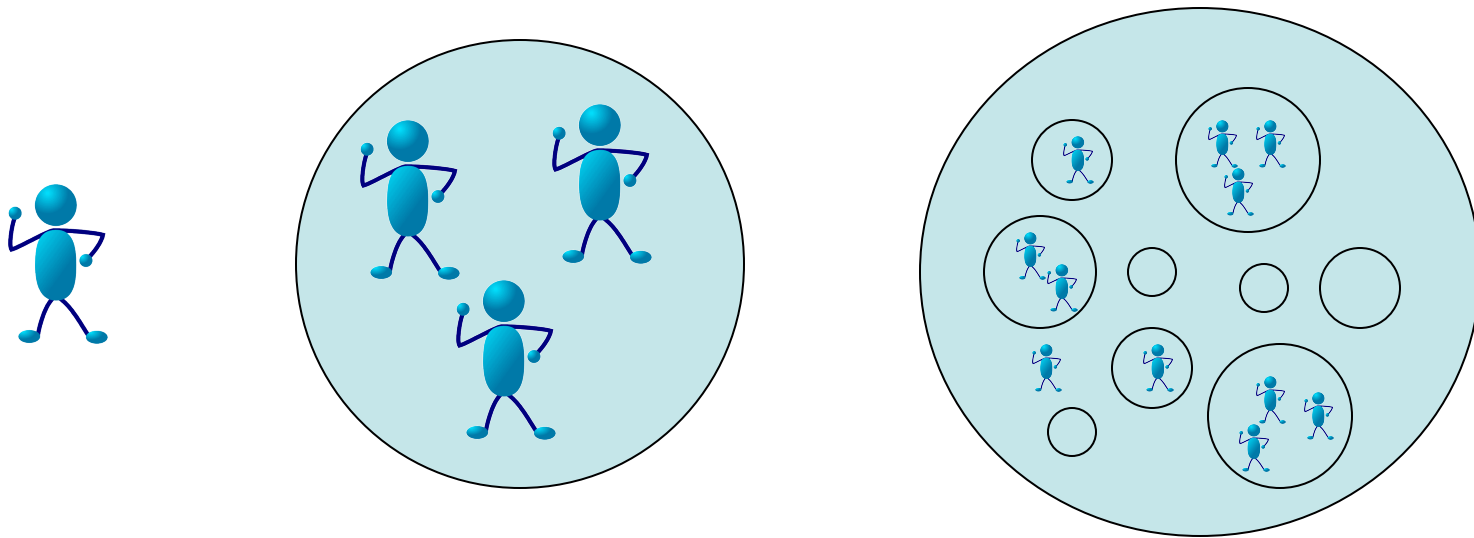
Society and Prediction: *Zeitgeist*



Genetics and Human Society

- Medicine (genetic testing, gene therapy, cloning, pharmaceuticals)
- Health care (practices, policies)
- Industry (chemicals, energy)
- Agriculture (GM crops/food)
- Legal and regulatory systems
- Domestic politics
- International/Global

The Levels of Analysis: Individual, State/Group, System



How did we get here?

Personal genomics has a history...

26 June 2000

Announcement of the sequencing of the human genome, after an effort that took 13 years at an estimated cost of 2.7 - 3 billion dollars.

President Bill Clinton

"Today, we are learning the language in which God created life. We are gaining ever more awe for the complexity, the beauty, and the wonder of God's most divine and sacred gift."

But...

...the announcement was premature. A truly complete sequencing of the genome was not accomplished until 2003.

...and it was a competition!

Philosophical Divisions

Some scientists (i.e., Venter and his company Celera) energetically pursued patents on various gene sequences, with a view to the commercial potential of the patents

Other scientists (Collins) saw gene sequences as public goods

Enter President Clinton..

- In March 2000, President Clinton announced the genome sequence could not be patented and should be made available free to all researchers.

...Exit stock value.

- The announcement sent Celera's stock value into a nosedive, and biotechnology stocks lost \$50 billion in market capitalization in two days.

Raising Hopes

Sequencing the human genome promised much: greater understanding of disease; improved medical treatments; and more effective pharmaceuticals

...but more than 20 years later, few results.

Raising Hopes Again

There are signs that breakthroughs are coming...for example, genetic screening of pregnant women for trisomies.

A trial study published in the New England Journal of Medicine found that 3.6 percent of standard tests for trisomies returned false positives, while only 0.3 percent of Illumina's Verify test returned false positives.

The implications are significant: fewer pregnant women would need to go through amniocentesis or chorionic villus sampling, which carry a risk of miscarriage.

The Potential

Human genome sequences can be compared with each other and with those of other species to reveal gene function and improve understanding of species evolution, genome functions, and the development of disease.

The Potential

Pharmacogenomics promises the ability to match drugs to a patient's genome, and avoid adverse drug reactions.

The Potential

Greater understanding of the genetic aspects of aging could lead to life extending treatments and improved quality of life.

Venter is at it again...with Human Longevity Inc.

“This is Celera on
steroids and cocaine.
We would have done
all this 13 years ago if
we could have.”

The Potential

Our understanding of human life and our relationship to the natural world, of human origins and evolution, will increase dramatically.

Concerns in the literature

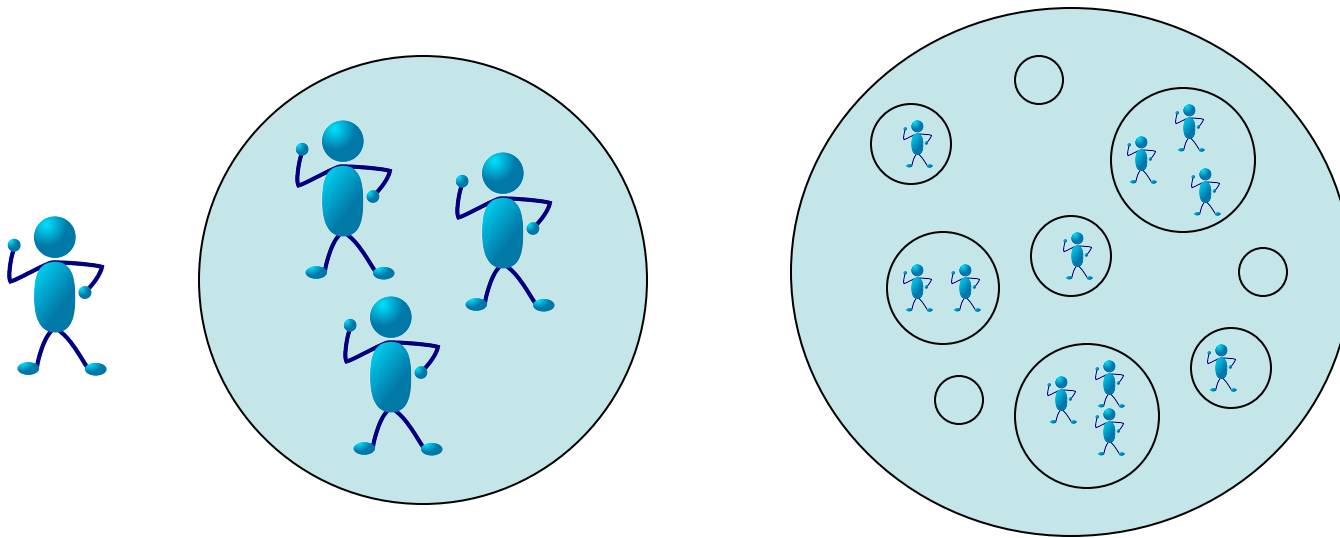
- Abuse of the technology
- Public education and awareness
- The role of law and government regulation
- Individual rights and privacy
- Reproductive ethics
- Patient and physician relations
- Potential for social engineering
- Genetic discrimination
- Racial and minority group marginalization
- Global governance and unequal distribution of benefits

Personal Genomics and the Social Sciences and Humanities

Core Themes

1. Analytical and policy complexity

The Levels of Analysis: Individual, State/Group, System (Global?)



Personal Aspirations

Standard of living

Education

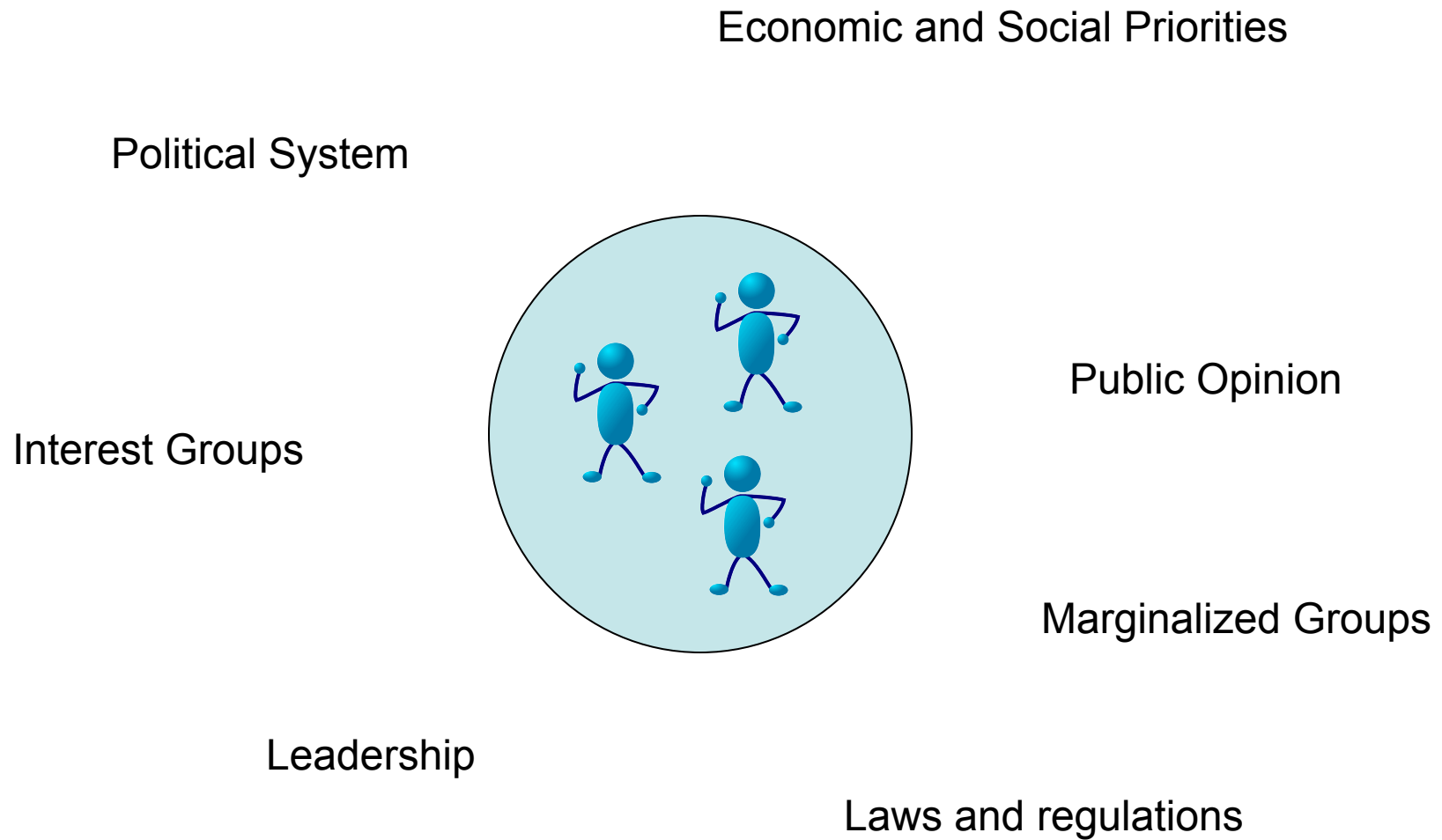
Spiritual Beliefs

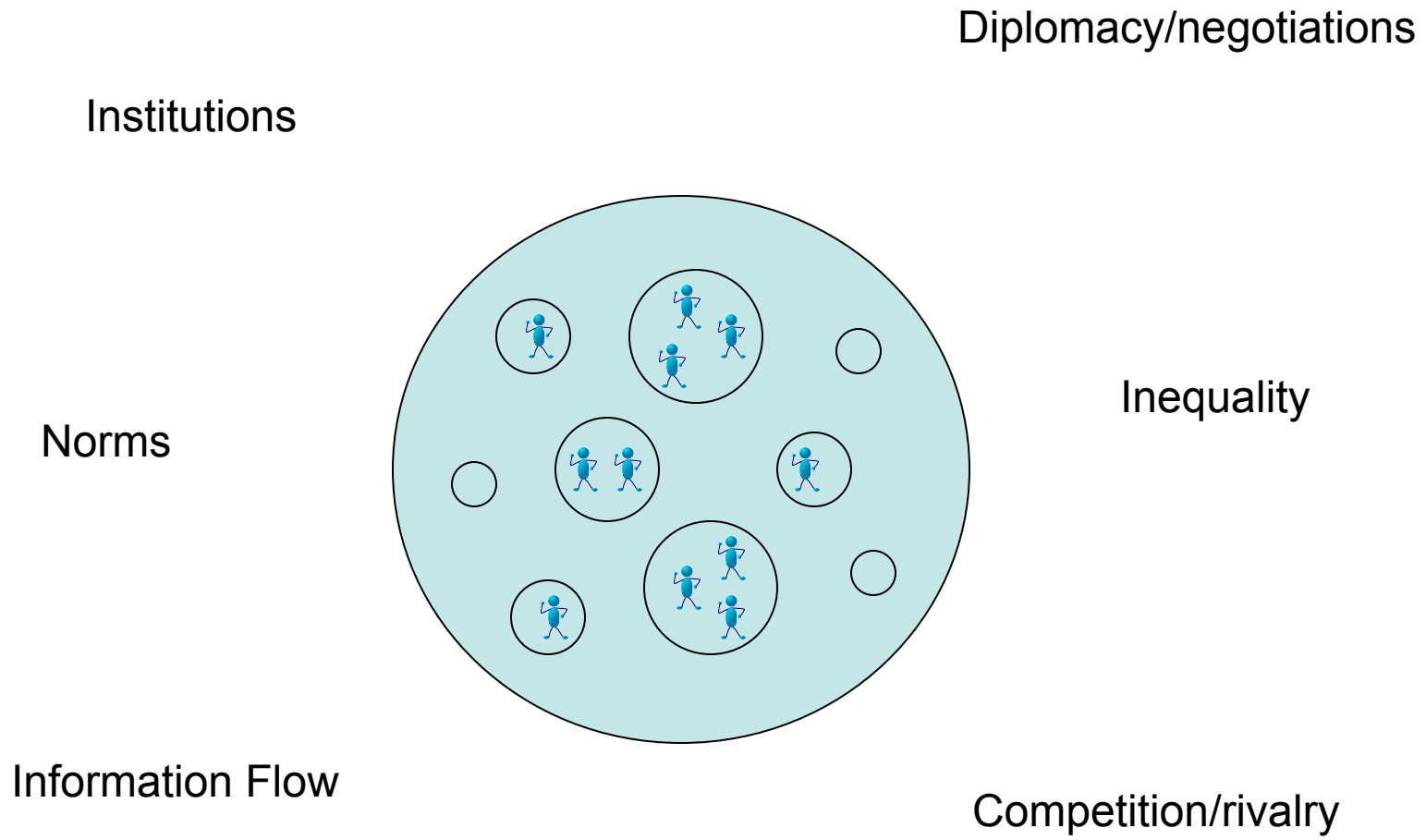
Life Experiences

Personal Ethics

Personal Health







2. The genie is out of the bottle

- Accessibility is increasing as costs fall and more genetic information is openly available.

2. The genie is out of the bottle

- Genetic privacy in the Information Age

CSI ASIC 200:

From Anonymous Genome to Individual Identity?

