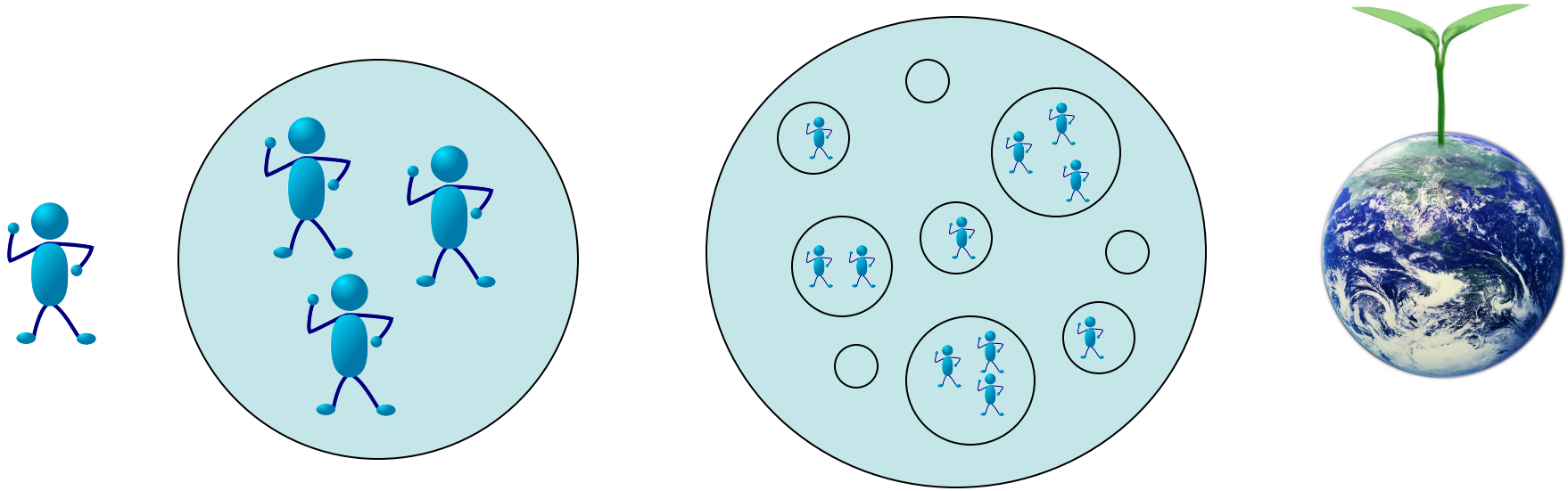
Personalized Genomics, Groups, and Global Governance

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



Genomics and Religious Groups

Playing God?

The Tale of The Prince and The Biologist.

Charles Philip Arthur George
(Prince)

- “Mixing genetic material from species that cannot breed naturally, takes us into areas that should be left to God. We should not be meddling with the building blocks of life in this way.”

Richard Dawkins
(Biologist)

- “Almost every morsel of our food is genetically modified – admittedly by artificial selection not artificial mutation, but the end result is the same. A wheat grain is a modified grass seed, just as a Pekinese is a modified wolf. Playing God? We have been playing God for centuries!”

The Seven Deadly Sins

- Lust
- Gluttony
- Greed
- Sloth
- Wrath
- Envy
- Pride

The Original Punishments

- Lust
- Gluttony
- Greed
- Sloth
- Wrath
- Envy
- Pride

- Smothered in fire
- Eat rats, toads, snakes
- Put in boiling oil
- Thrown in snake pits
- Dismembered alive
- Put in freezing water
- Broken on the wheel

The Seven Deadly Sins 2.0

- Lust
- Gluttony
- Greed
- Sloth
- Wrath
- Envy
- Pride

- Genetic modification
- Human experimentation
- Polluting the environment
- Social injustice
- Causing poverty
- Financial gluttony
- Taking drugs

Christian Ethics and Genomics

Christian ethicists believe that using genome-sequencing technology to determine behavioral choices should be the lowest priority in personal genetic research.

Instead, genetic research should emphasize the care and management of patients and in developing new treatments. Behavioral genetics does not do these things.

Islamic Ethics and Genomics

In the Islamic world, the approach taken toward genetics is grounded in the decisions of The Islamic Jurisprudence Council of the Islamic World League (Organization of Islamic Cooperation).

Islamic Ethics and Genomics

In its 15th session (Oct.) 1998 the IJC decided:

1) to permit use of genetic engineering for disease prevention, treatment, or amelioration on the condition that such uses do not cause further damage;
2) to forbid the use of genetic engineering for evil and criminal uses or what is forbidden religiously;
3) to forbid using genetic engineering and its tools to change human personality and responsibility, or interfering with genes to improve the human race;

Islamic Ethics and Genomics

4) to forbid doing any research or therapy of human genes except in extreme need, after critical evaluation of its benefits and dangers and after an official consent of the concerned, respecting the extreme confidentiality of the information and human rights and dignity as dictated by Islamic Sharia'ha;
5) to allow the use of bio-engineering in the field of agriculture and animals, on the condition that precautions are taken not to inflict harm (even in the long term) on humans, animals or vegetation.

Genomics and Group Identity

- Human and personal genomics can have a profound impact on cultural, ethnic, linguistic, and indigenous groups.

Genomics and Group Identity

- Indigenous groups around the world have taken a defensive stance concerning the genetic testing of their populations.

Genomics and Group Identity

- Indigenous groups worry about how the testing will be used and how it could hurt their cultural identity.

Arizona State University and the Havasupai Indians

"They used our blood for all these studies, people got degrees and grants, and they never asked our permission."

- Carletta Tilousi (Lead Plaintiff)

Genomics and Group Identity

- Arizona State University and the Havasupai Indians

http://www.nytimes.com/video/us/124746767 2743/blood-journey.html

Genomics and Group Identity

- Need for awareness of psychological impact and stigmatization due to a group's genetic differences.
  - *How does personal genetic information affect a group and society's perceptions of that group?*
  - *How does genomic information affect members of minority communities?*

Global Governance

“In the United States and in the West, you have a certain way. You feel you are advanced and you are the best. Blah, blah, blah. You follow all these rules and have all these protocols and laws and regulations. You need somebody to change it. To blow it up. For the last five hundred years, you have been leading the way with innovation. We are no longer interested in following.”

- Jian Wang, BGI president and co founder

Guidelines, but no rules

- There are currently no international institutions or international treaties solely responsible for the global governance of personal genomics.

Declaration of Bilbao (1993)

- The first international document to address the human genome. The declaration denounces all uses of genetic information causing or leading to discrimination in work relations, in the insurance domain or in any other sector.

UNESCO's Universal Declaration on the Human Genome and Human Rights (1997)

- proclaims that "[n]o one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."

UNESCO's International Declaration on Human Genetic Data (2003)

- specifies that "[e]very effort should be made to ensure that human genetic data … are not used for purposes that discriminate in a way that [infringes on] human rights, fundamental freedoms or human dignity of an individual … a family, a group or communities."

ECOSOC Resolution 2004/09 on Genetic Privacy and Non-Discrimination (2004)

- The United Nations Economic and Social Council's Resolution 2004/09 on Genetic Privacy and Non-Discrimination (2004) "[u]rges States to ensure that no one shall be subjected to discrimination based on genetic information" and to take the appropriate measures to attain this goal.

Global Governance

- NGOs and Networks

The Developing World

- The “genomics divide”

The Developing World

- 90% of health research dollars are currently being spent on health problems that affect only 10% of the world's population.

The Developing World

- Some expansion of genomic research into developing countries…

The Developing World

- …but using developing world populations for field testing is projected as the biggest role for developing countries.

The Developing World

- Genomic sovereignty
  - a state should exercise control over the genetic material of their populations.
  - desire to develop national expertise and infrastructure in this area, to avoid dependence and domination by foreign science and expertise.

The Developing World

- But…
  - Governments may be thinking of the genetic heritage of their populations as a resource, to be “mined” like any other.
  - Many groups in developing countries worry that governments will use genetic testing against them.

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