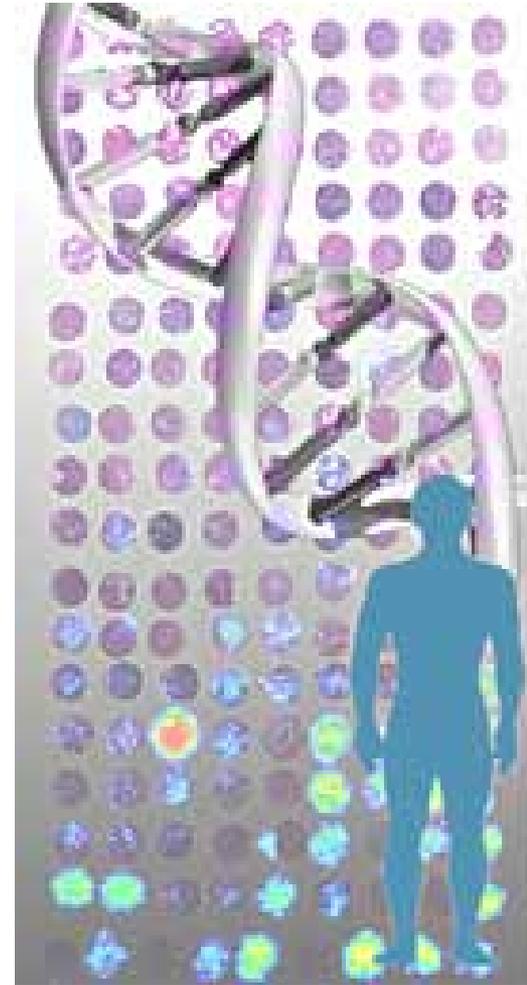


# Making Nano Work - Ethical, Educational, Economic, Legal and Social Issues

Pilar N. Ossorio, Ph.D., JD  
University of Wisconsin

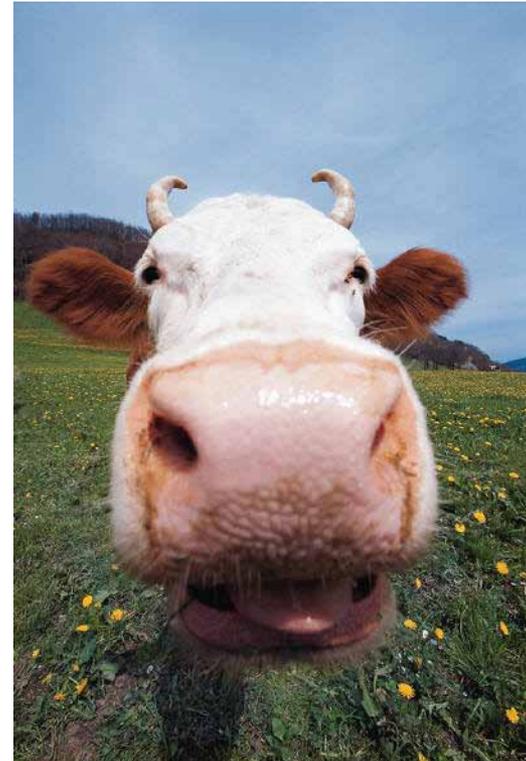
# HGP

- Human genome project (“official” HGP start was Oct. 01, 1990)
- Jim Watson, first director of the NIH Center for Human Genome Research, committed to studying social and ethical issues in 1988
  - Now the National Human Genome Research Institute



# HGP ELSI Program

- Ethical, Legal & Social Issues (or implications) - **the ELSI Program**
- NIH: 5 - 6% of genome budget since 1992; DOE also funded ELSI



# NHGRI ELSI Program

- Program funds work in philosophy, history, cognitive psychology, sociology, anthropology, law, political science, religion, education and public policy.
- Often, ELSI question is not whether some area of genomics research is permissible, but HOW we should do it.
  - Tech does not determine social outcomes - how can we develop and deploy the tech so as to produce socially desirable outcomes?
    - Who decides what counts as a socially desirable outcome?

# ELSI - Some Lessons

- Good ethics and policy work starts with good information
  - ELSI work should be based on up-to-date knowledge of genetic research practices, genome data, and “realistic” predictions of future scientific directions.
  - More integration of ELSI scholars with genome scientists
    - Geneticists are sometimes collaborators and sometimes research subjects for ELSI researcher

# ELSI - Some Lessons

- Not all of the relevant knowledge is found among geneticists...
  - Users
    - Docs, patients, research participants
  - Other publics
  - Unexpected uses: consumer genetics
  - Forensics
- Program has to study non-medical and unexpected uses, and to make some predictions about these uses

# ELSI - Some Lessons

- Need both empirical and theoretical work in your portfolio
- Need a good mix of (a) policy relevant research with shorter term “pay offs”; and (b) more exploratory research with longer term, less certain payoffs
- Scientists and program have to give some indication re. what is or will be relevant (through contracts and RFAs)

# NHGRI ELSI

- Program not without its critics
  - Watchdog or lap dog?



- Cooptation: Is ELSI merely legitimating the tech and pacifying the non-experts?

# NHGRI ELSI

- Criticism continued...
  - Obstructionism: ELSI hinders the progress of science, spending money on ELSI is worse than a waste.
  - Drift toward “moral and political triviality” because of focus on the “sci fi” questions rather than questions of practical importance.

# Nano ELSI ?

- Nano comprises a collection of tech that has the potential to remake social, economic and technical domains of life.
- Characteristics that invite heightened scrutiny -
  - novel properties, unobtrusive, embedded, ubiquitous, crosses formerly impermeable barriers
- Nano ethical, educational, economic, environmental, legal, & social issues = **NE<sup>4</sup>LS???**

# NE<sup>4</sup>LS

- 21st Century Nanotech Research and Development Act of 2003
  - Foresight, public engagement, integration
    - Foresight - develop scenarios of future uses and social impacts of nano (numerous methods)
    - Engagement with a variety of publics
    - Integrate new knowledge from foresight exercises and engagement into lab practices and nano policy
  - An iterative process for reflexivity in the development of nano research and policy

# Public Engagement

- Numerous methods
- Used widely in Europe and CA in health policy, biomedical research, nano and other contexts
- ELSI has also undertaken a variety of public engagement and consultation activities
  - Widely criticized in many contexts

# Public Engagement

- Who should be engaged and why?
  - Which publics? Which members of each public?
- What is the goal of the engagement?
  - Elicit attitudes or beliefs
  - Elicit values
    - Weighting of various options or outcomes
  - Elicit knowledge or concerns
  - Identify unanticipated risks and learn relevant language
  - Demonstrate respect for individuals and communities, and advance civic engagement
- What methods will best achieve the goals?

# Public Engagement

- What metrics do you use to assess engagements?
- **What do you do with the information from public engagements?**
- Geneticists generally do not like them...
  - High \$\$ cost, very time consuming, ambiguous info produced

# NE<sup>4</sup>LS

- Privacy
- Potential to exacerbate inequality
- Potential for human enhancement and challenges to the nature of human identity
- Safety issues
  - For users and bystanders
  - Workplace exposures

# NE<sup>4</sup>LS

- Nanomedicine
  - Life extension
    - Affects on Medicare and Social Security
    - Affects on family relations and family structure
    - Affects on work force and work life

# Difficulties for NE<sup>4</sup>LS

- Protean subject matter-encompasses many types of tech
- With applications in a variety of fields
- That are governed in a variety of ways
- By a variety of agencies and other stakeholders
  
- Undefined time horizons for the emergence of various types of nanotech.

# Emerging Tech Policy

- There will be some overlap between the ethical, educational, legal, and social issues relating to nanotechnology and those relating to genomics.
- Perhaps we ought to be thinking more broadly about an program for studying the social issues of emerging technologies generally????