



# INCLUDING GENOMICS IN SOCIAL SCIENCE RESEARCH: ETHICAL ISSUES

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# Agenda



- A. A brief history of the eugenics movement
- B. A non-exhaustive list of things that should keep you up at night as you embark on this work
- C. Some emerging best practices for responsible conduct and communication of social science genomic research

# A Brief History of the Eugenics Movement, 1870-1950



Two versions of the history of the eugenics movement:

**“Official” version** (taught to new geneticists & bioethicists; dominates popular understanding): racist, reactionary thinkers and politicians, working with a few marginal scientists; direct line from Darwin to Hitler (and Trump?)

**“Real” version** (much harder to teach; less reassuring; bioethical lessons far less obvious): remarkably large and diverse membership divided on beliefs and proposed interventions

SOURCE: Leila Zenderland, “What was Eugenics?,” unpublished paper presented at the American Philosophical Association, Pacific Division, 1998 (described in Buchanan et al., *From Chance to Choice*, Cambridge UP 2000)

# A Global, Mainstream Movement

- Apex of the movement—the Third Reich—has (mostly understandably) overshadowed other aspects of the movement that are critical to understand
- UK, US, France, Brazil, Canada, Sweden, Denmark, Norway, Russia/Soviet Union, Germany
- Diverse disciplines: medicine, sociology, anthropology
- Diverse beliefs in how parental traits are transmitted to offspring:
  - Lamarckian (France, Brazil): transmission largely environmental
  - Germ plasm theory (Anglo-Saxon): transmission genetic; medicine interfering with natural selection
- Demographically heterogeneous (ish): e.g., women, Jews
- Funded by Rockefeller and Carnegie Foundations

# Rapid Adoption Despite Minimal Evidence

- Galton (Darwin's cousin)
  - Observed clustering of scientific, literary “genius” in a few families
  - Goal: to improve society's stores of talent and virtue
  - Means: encourage favored families to increase reproduction; encourage disfavored families to decrease reproduction
  - “Eugenics”: “science of improving stock—not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had” (1883)
- Widespread, nearly immediate influence among middle- and upper-middle classes, including many academics, politicians, and other professionals
  - In US and UK: eugenics both a research program and a popular movement
    - Carnegie Foundation funded Eugenic Record Office under sociologist Charles Davenport: collected pedigrees
    - Eugenics standard in biology textbooks
    - “Fitter Families” competitions at state fairs
    - “public health” norms emerge: “private” reproductive decisions could wreak havoc on society for generations
    - Average American vs. “white trash” → extends well beyond Galton's genius

# Diverse Ideologies (Kevles 1986)

## Mainline/Reactionary eugenics:

- *Mostly* politically conservative
- Classism: “a middle-class activism focused upon the pauper class, with a biological view of human failings” (Mazumdar 1992), e.g., poverty, prostitution, crime, alcoholism
- Racism: e.g., southern/eastern Europeans were view as inferior
- Nationalism: nation-level competition over gene pool quality

## Reform/Progressive:

- Typically left-of-center, e.g., Progressives (US), Fabian Socialists (UK), Social Democrats (Norway, Canada), father of Danish welfare state
- Often rejected mainline eugenicists’ assumptions: e.g., that genetic contribution to talent could be assessed in country w/o equal opportunity
- But thought this was both scientifically possible and morally laudable in socialist countries
- E.g., Sweden: justified tens of thousands of state sterilizations by savings that could be allocated to cradle-to-grave social security
- “Geneticists’ Manifesto” (1939): reproduction to optimize health, intelligence, pro-sociality; someday, everyone will look at “genius” as his or her birthright
- *Most* still exhibited racism and classism; eugenic targets typically stigmatized, vulnerable

Opposition to eugenics: Came mostly from the political right, esp Catholic Church

# Diverse Policy Commitments



- “Positive eugenics”: encouraging fertility of most “fit”
  - e.g., family allowances, marriage advice clinics, mass insemination of women with sperm of a few distinguished men
- “Negative eugenics”: curbing fertility of least “fit”
  - e.g., sexual segregation (anti-miscegenation and anti-immigration laws), involuntary sterilization, euthanasia, murder
- Typically opposed to birth control (fear that the “fit” would use it), but some feminist eugenicists supported reproductive control as a means of improving the gene pool
- Many accepted state coercion; others wanted eugenic practices to be voluntary (e.g., those who emphasized positive eugenics; Galton wanted to convert eugenics into a civic religion)

# Common Themes



Features uniting otherwise heterogeneous movement:

- 1) Fears of catastrophic degeneration
  - Environmental causes of degeneration (e.g., industrial revolution)
  - Germ plasm theory and “unnatural selection” (modern society rescuing the “unfit”)
  - Loss of racial purity (mixed-race offspring viewed as less fit than either parent)
- 2) Belief in the strong heritability of behaviors (based on very little evidence)
  - E.g., sociologist Davenport: Pauperism, love of the sea (assumed to be sex-linked since sea captains were all male)
  - For many eugenicists, key trait was intelligence (e.g., immorality thought to result from inability to distinguish right and wrong)
- 3) Goals
  - Concern for human betterment through selection
  - Improve overall quality of the gene pool (via positive or negative eugenics)
  - Of necessity at the time, policy levers all involved reproductive practices
  - Reproduction seen as an act with social consequences, not a private choice
  - Germ plasma seen as a social resource whose use should be governed by public good

# A Brief History of the Eugenics Movement, 1870-1950



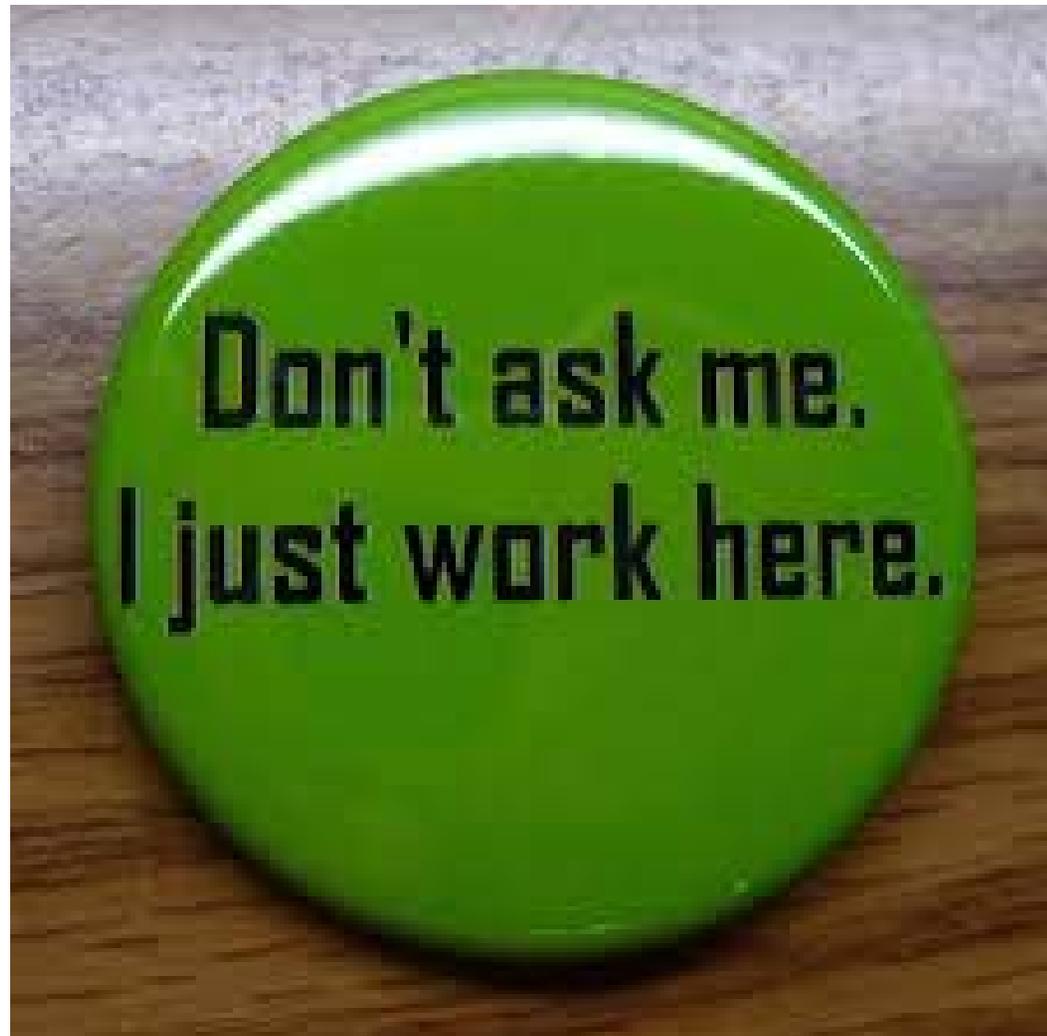
Not an academic discussion:

- Is genetic determinism in the general public significantly less prevalent today than in was during the eugenics movement?
- Is there today less of an interest in avoiding the conclusion that social problems are significantly rooted in institutions and structures?

Buchanan, Brock, Daniels, Wikler, *From Chance to Choice: Genetics & Justice*  
(Cambridge UP, 1<sup>st</sup> ed. 2000)

# Different Rules

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# DURC: An Analogy?



Dual Use Research of Concern (DURC) is life sciences research that, based on current understanding, can be reasonably anticipated to provide knowledge, information, products, or technologies that could be directly misapplied to pose a significant threat with broad potential consequences to public health and safety, agricultural crops and other plants, animals, the environment, materiel, or national security. The United States Government's oversight of DURC is aimed at preserving the benefits of life sciences research while minimizing the risk of misuse of the knowledge, information, products, or technologies provided by such research.

# A Non-Exhaustive List of Things That Should Keep You Up at Night



- What are the potential benefits of my work? Do they justify these risks?

# Genetics and human behaviour

the ethical context

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concerns about the potential applications. **We take the view that research in behavioural genetics has the potential to advance our understanding of human behaviour and that the research can therefore be justified. However, we note that it is important that those who fund research in this area should continue to fund research of a high calibre, should be transparent about their funding practices and should be aware of the potential for the abuse and misinterpretation of results. In addition, we recommend that research sponsors who intend to focus strategic funding in this area should pay careful attention to public concerns about the research and its applications (paragraph 11.17).**



*We heard profound concern that the research would further disadvantage people who are already disadvantaged yet no arguments that it should come to a halt.*

— Special Report, *The Genetics of Intelligence: Ethics and the Conduct of Trustworthy Research*, *Hastings Center Report* (2015)

# A Non-Exhaustive List of Things That Should Keep You Up at Night



- What are the potential benefits of my work? Do they justify these risks?
- How would the people whose data I'm using feel about my work?

Topic	% rating as inappropriate	Unrelated to health	Unrelated to genetics	Unfair treatment or prejudice	Other
Income	46%				
Religious Belief	45%				
Religiosity	41%				
Econ/Pol Prefs	40%				
Econ. Stability	31%				
Sexual orientation	21%				
Education	20%				
STDs	17%				
Personality	14%				
Race/Ethnicity	14%				
Optimism	13%				
Intelligence	11%				
Happiness	10%				

- The problem: Broad & blanket consent
- Population: Geisinger MyCode biobank participants
- $N = 3,387$  (response rate: 11%)
- Diverse (stratified and oversampling)
- Joint work with Geisinger colleagues: Dan Davis, Jen Wagner, Andy Faucett, Patrick Heck, Anh Huynh

# Baseline Inappropriate/Unsure Ratings: Most Important Reason (across all topics)

<u>Respondent</u> <u>Race/</u> <u>Ethnicity</u>	Unrelated to health	Unrelated to genetics	Potential unfair treatment or prejudice	Other
All				
White				
Non-White				

# A Non-Exhaustive List of Things That Should Keep You Up at Night



- What are the potential benefits of my work? Do they justify these risks?
- How would the people whose data I'm using feel about my work?
- How would non-data subjects who are nevertheless likely to be especially affected (e.g., subjects' relatives, groups) feel? [Student question]

# The Havasupai Tribe Case



- Oral discussion: diabetes study
- Written consent: “study causes of behavioral/medical disorders”
- Allegedly studied: schizophrenia, consanguinity, population migration
- Lawsuit:
  - \$1.7m litigation costs
  - \$700,000 settlement
  - Returned 151 remaining samples
  - Redaction of publications
- Example of “group harm”

# A Non-Exhaustive List of Things That Should Keep You Up at Night

- What are the potential benefits of my work? Do they justify these risks?
- How would the people whose data I'm using feel about my work?
- How would non-data subjects who are nevertheless likely to be especially affected (e.g., subjects' relatives, groups) feel? [Student question]
- Is communication/application of my work getting ahead of the science/evidence?
- Will my work be misinterpreted?
- Will my work be misused?
  - Stigma (of self and/or others)
  - Discrimination (employment, education, healthcare, various insurances, reproduction/adoption policies)?
- Will my work exacerbate existing—or create new—inequalities?
  - “Negatively,” via stigma or discrimination
  - “Positively,” via benefits that extend only to those of European ancestries and/or to the wealthy
- What can I do to minimize the risks of my work?

Publications

Data

Phenotypes

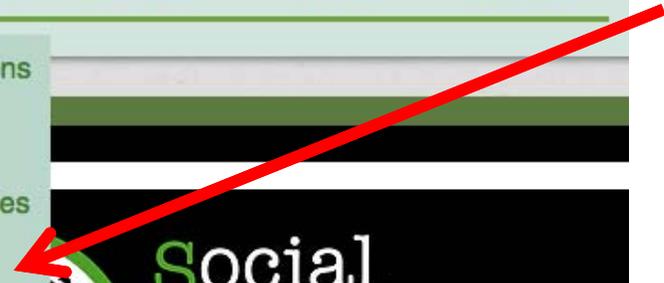
FAQs

# Welcome to the Social Science Genetic Association Consortium (SSGAC).

The SSGAC is a cooperative enterprise among medical researchers and social scientists that coordinates genetic association studies for social science outcomes and provides a platform for interdisciplinary collaboration and cross-fertilization of ideas. The SSGAC also tries to promote the collection of harmonized and well-measured phenotypes.



Social  
Science  
Genetic  
Association  
Consortium

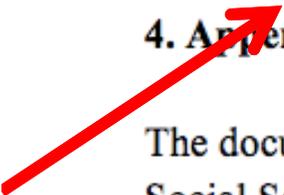




## **Frequently Asked Questions (FAQ)**

This description of the *Nature* paper “*Genome-wide association study identifies 74 loci associated with educational attainment*” includes the following information:

- 1. Background: authorship, goals, definition of “educational attainment,” previous research**
- 2. Study design and results: genes, variants, and biology linked to educational attainment**
- 3. Social implications of the study: potential use in medical research and in policy**
- 4. Appendices: quality-control measures, further reading and references**



The document was prepared by several co-authors of the paper and Advisory Board members of the Social Science Genetic Association Consortium. For clarifications or additional questions, please contact Daniel Benjamin ([djbenjam@usc.edu](mailto:djbenjam@usc.edu)).

**“Scientists have a responsibility to do what they can to prevent abuses of their work.”**

Finally: be proactive. Once scientists are sure of their results, they usually do their best to explain the significance of their work in academic publications. But these texts are often impenetrable to the public and may include technical terms that can be misinterpreted by non-specialists. To provide clarity, scientists would do well to follow the example of the Social Science Genetic Association Consortium. In June, this group published a paper on genetic variants associated with educational attainment (C. A. Rietveld *et al. Science* 340, 1467–1471; 2013). Accompanying this was a nine-page Frequently Asked Questions document that, in plain, easy-to-understand language, addressed such questions as why the researchers did the study, what they found and what the implications of the work are — and are not (see [go.nature.com/7mov2j](http://go.nature.com/7mov2j)). The document spelled out that the consortium had not found ‘the gene’ for educational attainment, that each genetic marker found has only a very small effect on length of schooling, and that any policy response based on that single study would be premature.

Nature (2013)



Fortunately, efforts at guarding against hyperbole are already under way. In 2013, a group of researchers—the Social Science Genetic Association Consortium—published an article in *Science* on three genetic variants that are associated with educational attainment (which they took to be a proxy for intelligence) and simultaneously posted an essay that explained in plain English how the study was conducted and what it did—and did not—find.<sup>16</sup> They explained why they had not found “the gene for educational attainment” and why it would be “extremely premature” to infer policy implications from their findings. While the SSGAC may be the best example of prophylaxis against hyperbole to which we can point, other contributors in this collection (see the contributions by James Tabery, Sarah Richardson, and Shawneequa Callier and Vence Bonham) offer examples of behavioral or population geneticists who have taken similar steps.

Hastings Center Report  
(2015)

# Other Emerging Best Practices



- Very high standards for study design
- Data sharing
- Replication
- Science communication
  - Hying results → emphasizing limitations
  - *Active* communication of what results do—& don't—mean
  - Seek out responsible science journalists
  - Correct media errors
- Rapid responses to bad science (Erik Parens)
- [Watch this space]



**Questions?**