Social Issues in Biology: A framework for discussing responsible conduct and ethics with science trainees

Kayla Davis, PhD February 26, 2022



#### **Social Issues in Biology**



**Dr. Jon Beckwith** 



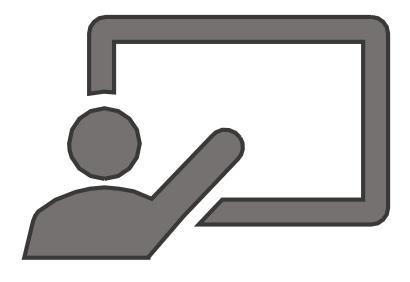
First to isolate a gene from a bacterial chromosome in 1969



Launched the Harvard Medical School Social Issues in Biology Course



Working to make the Social Issues in Biology course syllabus open access in the next year



#### **Outline**

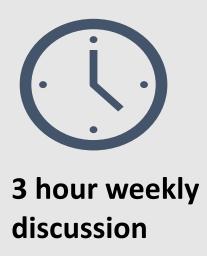
Course structure

 Leading a productive and respective discussion course

Examples of course materials

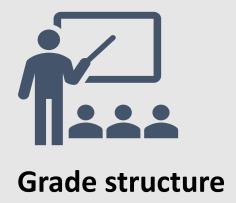
#### **Course structure**







Missed course assignment



# Models for teaching RCR in the classroom

- Case studies
- Current events
- Independent reading followed by informed discussion
- Faculty led question-based discussion
- Guest lecturers
- Role play discussions
- Student teaching

# Course discussion topics

- How Genetics is Taught and Communicated
- Eugenics: Past, Present, and Future
- Reproducibility in Science as an Ethical Issue
- Sexism in Science and the Biological Definitions of Sex
- Indigenous Ways of Knowing in Science
- Past Silencing of Minority Voices
- Science in Warfare and Science Activism



## Creating a culture that values RCR and science ethics

- RCR is viewed as just as important for training as other course work
  - Create a course that goes beyond the requirement
  - Identify faculty and guest lecturers that are passionate about the subject topics
  - Encourage departments and faculty to make research conduct and responsibility a part of their programming



## Creating a culture that values RCR and science ethics

- Provide recognition and reward opportunities for faculty who participate in RCR courses
- Support trainees who want to do more than the requirement



## Creating a culture that values RCR and science ethics

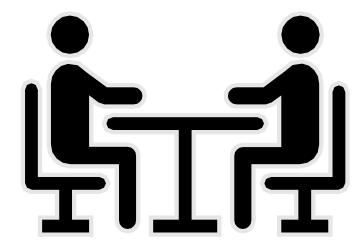
 A culture of responsible scientific conduct where folks feel comfortable speaking out, promotes an overall safe and productive culture for staff and trainees

## Questions?



#### Civil discourse

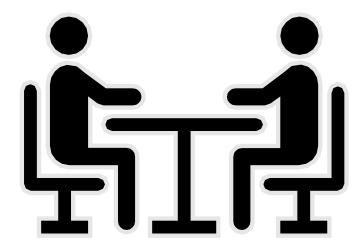
- Establish class rules for format and discussion
- Acknowledge that conversations may be uncomfortable
- Gear conversation through specific discussion questions
- Encourage open discussion but have prepared questions to steer the conversation back on topic
  - "Thanks for that input, Taylor, I'd like to get back to the discussion on Y, but we can chat more about that after class if you'd like."



#### Civil discourse

 Recognize history of inequities in science and present cultural, structural, and systemic barriers that exist in science

 Encourage students to bring their whole self to the conversation



# Concerns of saying the wrong thing or not being an expert



Don't pretend to be an expert!



Recognize when you learn something new from students



Acknowledge lack of knowledge or personal experiences



Acknowledge privileges

# Teach trainees how to report misconduct and harassment

 Provide students with clear ways to report issues of scientific misconduct or forms of harassment

- Explain the processes that follow reporting
  - make sure students are aware of ways to report conduct and harassment beyond the university system

## Questions?





### Research Framework

Refers to multiple aspects of the project...

- 1) Why is the experiment being considered?
- 2) What type of experiments need to be done?
- 3) How will the experiment be designed?
- 4) How will the data be analyzed?
- 5) What can be obtained from an experiment?
- 6) How does one use the experimental results?
- 7) Does the experiment have the potential for societal impact? How?

# Scientific Hypothesis vs Question? Is hypothesis always best?

Hypothesis: The Sky is Red

#### **Experimental Design:**

- Determine the wavelength of light which causes a "red" readout, using a positive control known to be red.
- Set a wavelength-meter to signal when the color red is detected.
- As a negative control set a second wavelength meter to detect any color other than red.
- Collect data over 24 hours.

# Scientific Hypothesis vs Question? Is hypothesis always best?

- See if you got a "positive" readout.
- Repeat the experiment ten times times.

Hypothesis: The Sky is Red

Nine out of ten times, the color red has been positively detected.

Conclusion: The sky is red (or the hypothesis is not falsified)

#### Scientific Hypothesis vs Question?

Might one conclude from this experiment that the sky is red?

- 1) Need to establish the "usual case"
- 2) Need to establish definition of terms
- 3) Scientific disagreements are often about "semantics"

does the hypothesis mean "red appears in the sky?" or does it mean "the sky is usually red?"

Semantics are important

#### Considerations for hypothesis based science

1) The hypothesis mirrors the conclusion

Hypothesis: The Sky is Red

Conclusion: The Sky is Red

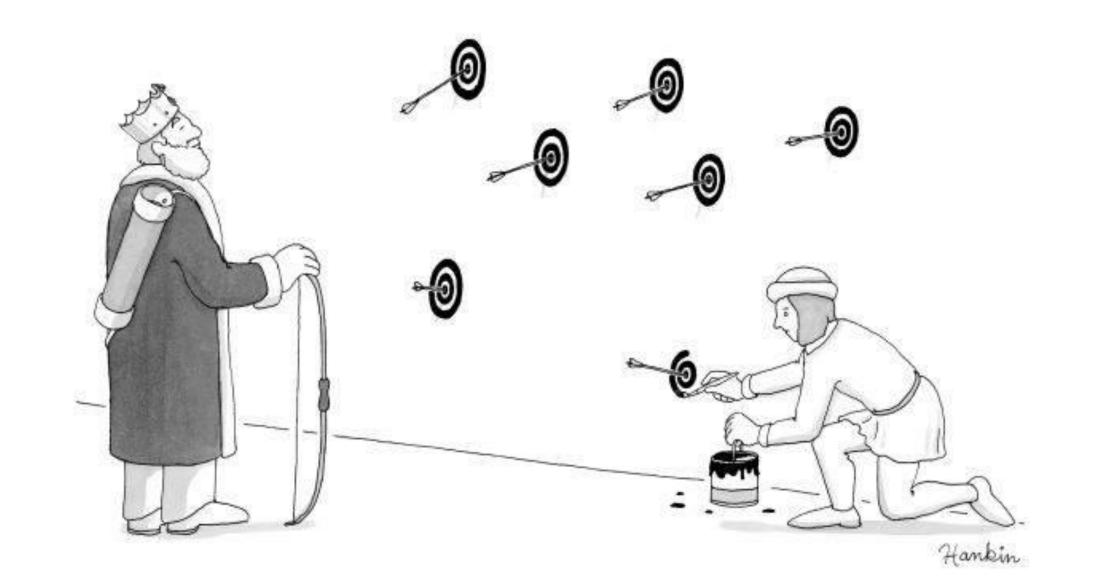
Hypothesis: Ingestion of caffeine induces the likelihood of cancer

Conclusion: Ingestion of caffeine induces the likelihood of cancer

This formulation can make the experimenter confuse the unproven with the proven

#### Considerations for hypothesis based science

- 1) Falsification is not rewarded
- 2) Experiments are aimed at confirmation, because of the requirement to measure the "positive" result therefore there is a tension between the experiment and the philosophical paradigm framing the experiment
- 3) The negative data may be inappropriately used as a filter that = lack of positive data, as opposed to "not positive"



## Questions?



Responsible Science
Communication and
the Importance of
Responsible Scientific
Collaboration

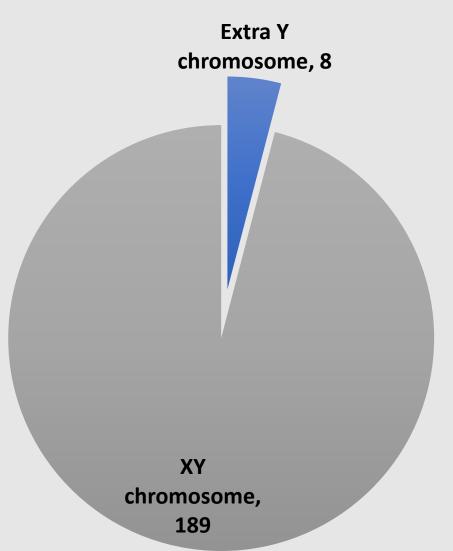


Published: 01 December 1965

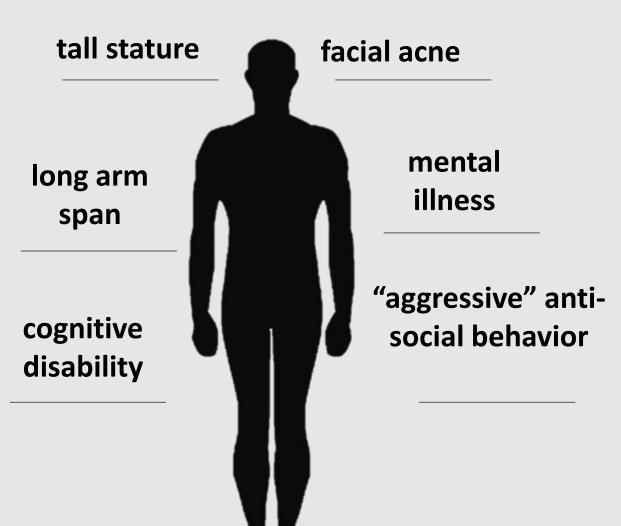
## Aggressive Behaviour, Mental Sub-normality and the XYY Male

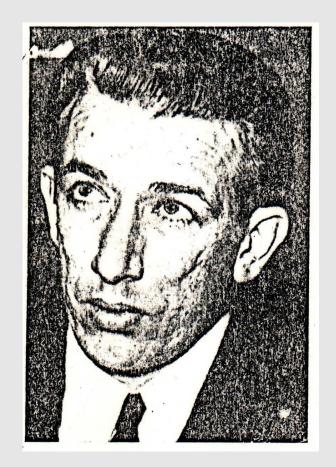
PATRICIA A. JACOBS, MURIEL BRUNTON, MARIE M. MELVILLE, R. P. BRITTAIN & W. F. MCCLEMONT

"Building on previous studies, if an extra Y chromosome predisposes its carriers to unusually aggressive behaviour, then we might expect an increased frequency of XYY males among those of a violent nature."



- Surveyed population in Swedish prisons have approximately 3.5% XYY males
- General population has approximately .2% XYY males
- "It is not clear whether the increased frequency of XYY males found in this institution is related to their aggressive behavior or to their mental deficiency or a combination of those factors"



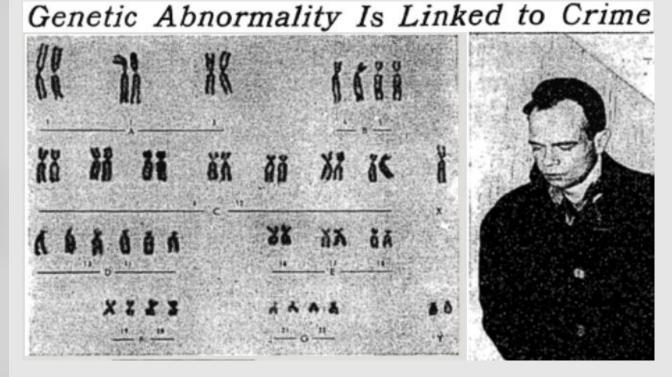


Richard Speck

# THE XYY AND THE CRIMINAL

October 20, 1968

by Robert W. Stock

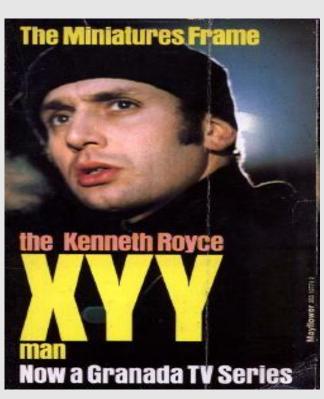


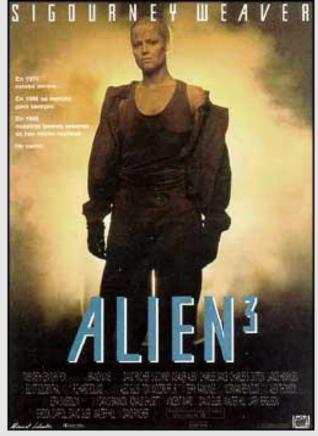
 By 1975, there was enough evidence from further studies to demolish the myth of the "criminal chromosome"

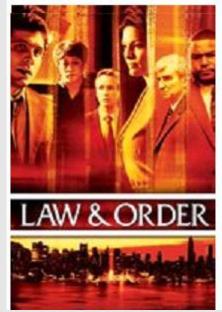
"In retrospect, I should not have used the words 'aggressive behavior' in the title of my paper and should not have described the institution as a place for 'the treatment of individuals with dangerous, violent or criminal propensities." (Am. J. of Human Genetics)

-Dr. Patricia Jacobs

#### But the myth persisted in pop culture for decades







Born Bad (TV episode 1993 #4.9)
The lawyer of a 14-year-old boy claims he is not responsible for the beating death of his friend because he has an extra Y chromosome and is genetically predisposed to criminal behavior.

16 November 1993

- Thousands of Black children in Baltimore were screened for XYY at Johns Hopkins Medical.
- Amniocentesis and abortion of XYY males
- Stigmatization of XYY children
- Research screening of baby boys for XYY, some using approaches with serious ethical problems
- Politicians, the media, and others generalized, arguing that criminality was genetically determined, not the result of poor social and economic environments

#### Māori "warrior gene"

 A single point mutation in the MAOA gene is linked to aggression and criminality in a Dutch family

> Science. 1993 Oct 22;262(5133):578-80. doi: 10.1126/science.8211186.

## Abnormal behavior associated with a point mutation in the structural gene for monoamine oxidase A

H G Brunner 1, M Nelen, X O Breakefield, H H Ropers, B A van Oost

#### Māori "warrior gene"

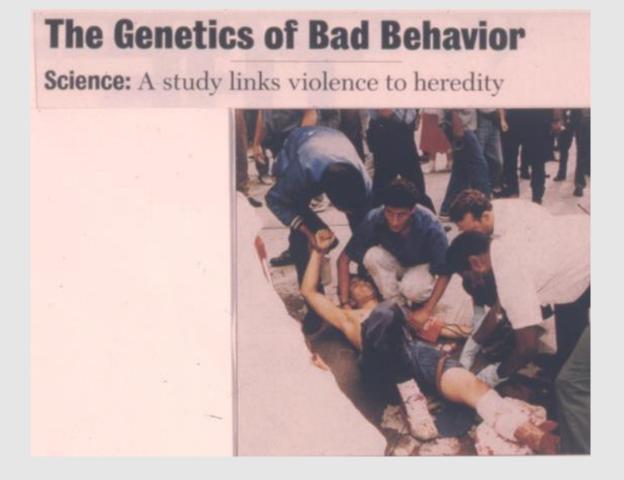
The MAOA gene has long been studied and related to aggression

**HUMAN GENETICS** 

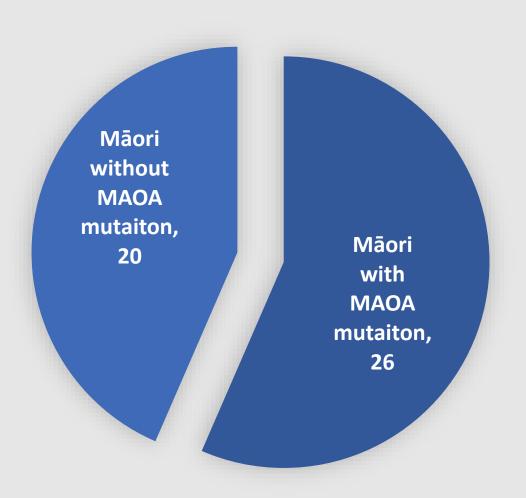
## Evidence Found for a Possible 'Aggression Gene'

Researchers in the Netherlands are hot on the track of a genetic mutation in a large Dutch family that may cause periodic outbursts of aggression in its possessors. In this

Brunner, a clinical geneticist, originally became interested in looking for the suspected "aggression gene" in 1978, when a woman serendipitously stopped by his office to



#### Māori "warrior gene"



- In 2006, two scientists from New Zealand announced at a scientific conference their findings that the Māori people were more likely to have an MAOA point mutation linked to aggression (56% of the 46 Māori people surveyed compared to 30% with European ancestry)
- They claimed that the presence of a "warrior gene" had been positively selected for during "violent and risky" ancestral migration and that this gene could account for the warlike nature of the Māori society.

# The "gay gene": approaching a controversial topic with a cautious approach

## Large-scale GWAS reveals insights into the genetic architecture of same-sex sexual behavior



- Work done by someone in the studied population
- Met with special interest groups while designing and before publishing

### The "gay gene": approaching a controversial topic with a cautious approach

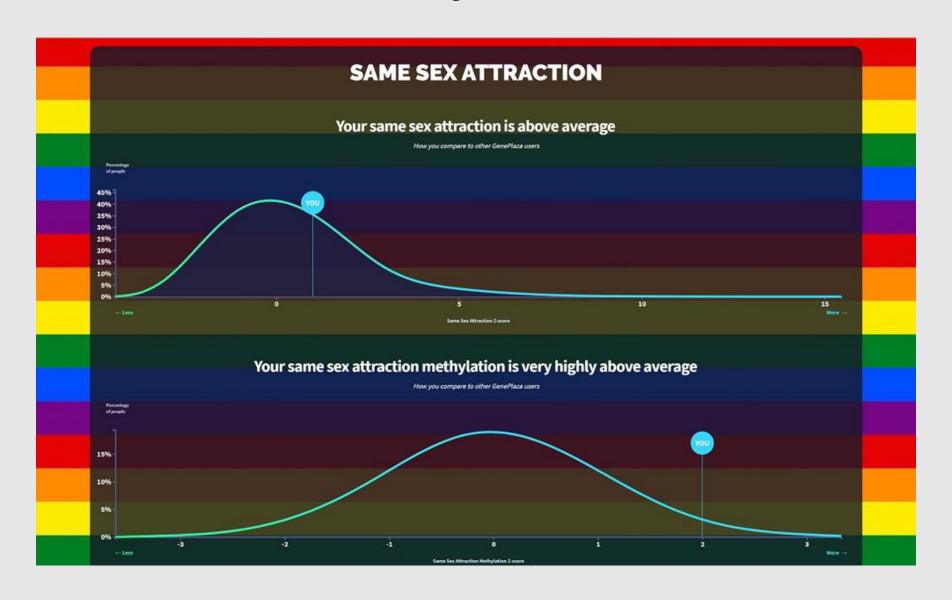
**NEWS** 29 August 2019

# No 'gay gene': Massive study homes in on genetic basis of human sexuality

Nearly half a million genomes reveal five DNA markers associated with sexual behaviour – but none with the power to predict the sexuality of an individual.

- Work done by someone in the studied population
- Met with special interest groups while designing and before publishing
- Media presence "there is no gay-gene" Andrea Ganna

#### "How Gay Are You?"



#### "How Gay Are You?"

"Pop culture owns this science now and it is going to keep getting spun to sell products or an ideology."

- Tim Caufield Bioethicist University of Alberta

#### Concluding thoughts....

- Scientists, even when they admit to regretting the outcome of their work have historically done little to debunk their mistakes or misinterpretations of their work.
- Inclusive science research design is a critical starting point for building trust in science.
- We don't always know what will be impactful, but we do have the power to be inclusive and intentional in every step of the scientific process.
- The publicity of scientific studies has the power to influence policy, cultural norms, or even harm people or populations.

#### Questions?



Indigenous Traditional Knowledge and Research Methodologies

## A brief overview of American Indian history and place

#### Political History

- Article 1, Section 8: Tribes possess a nationhood status and retain inherent powers of selfgovernment.
- 573 Sovereign tribal nations in the United States
- Each tribe retains unique relationship with federal government

#### Complex Land and Jurisdictions

- Allotted lands results of the federal allotment period
- Restricted status lands land that must be approved by the Secretary of the Interior to alienate or encumber
- State Indian Reservations land held in trust by the state

#### American Indian Health

- Shift from infectious to chronic disease as leading causes of mortality
- Indian Health Services

Negative colonization experiences of Indigenous Peoples in westernized nations

- HUGE population loss
  - Disease and warfare
- Loss of Culture
- Loss of Land
  - Loss of traditional environmental knowledge
- Language Loss
- Knowledge systems displaced
- Education systems displaced
- Legal systems displaced

#### What Are indigenous Research Methods?

"Unique ways researchers use Indigenous positionality and perspective to perform research with and within Indigenous communities . . . [that] center and privilege the Indigenous community's voice(s) in an effort to contribute to the community" Windchief et al. (2017)

# Why are Indigenous Research Methodologies important?

- Understanding communities leads to opportunities for improving social support
  - Increased social support leads to improved health behaviors and sustainability
- Cultural connectedness is a vital protective factor
  - Improved mental health
  - Improved physical health
  - Increased resilience
- Cultural connectedness and IRMs center around relational accountability
  - Interconnected relationships with people, land, and spirituality
- Indigenous research methods move beyond an indigenous perspective

## Many negative examples of (modern) Genetic technologies in Native Communities

- Arizona State University researchers misuse of Havasupai DNA and blood samples
- Navajo Nation banned all genetic research in 2002
- Ebola outbreak in Guinea
  - International clinical assistance however some international teams exported thousands of biomedical samples with associated clinical and personal data without consent for research. Effort to reclaim samples was unsuccessful.
- Nat Geos Human Genome Diversity Project-> low indigenous involvement and concerns around data interpretation conflicting with the Indigenous narratives 2000
- 'All of Us' Project-> no tribal consultation or articulation of benefits for indigenous groups 2019
- Trump vs Warren (and Bustamante) saga-> ancestry does not equal ethnicity

#### Common Themes of Negative Experiences

- Researchers prioritizing their own professional goals over the communities they're studying
  - Lack of benefits to community
  - Helicopter researchers- lack of trust
- 'On' not 'with'
- Lack of (re)consent
- Lack/ loss of transparency and community control -> publication of inappropriate narratives without prior approval
- No use of indigenous ethics -> lack of culturally appropriate framework for research

#### Indigenous Groups Interest in Genetics

- Many monogenic and polygenic conditions affecting indigenous groups
- High population of rare disease prevalence
- Pharmacogenetics- insights into drug response dependent on genetic make-up

#### **Potential Outcomes:**

- More effective health interventions
- Better diagnostics
- 'precision medicine' in indigenous communities
- Reinforce public health messages to community
- Dispel racist stereotyping that disease affecting indigenous groups is result of poor lifestyle choices

Thank you!

Questions?

