# Personal Genetic Code:
## Algorithmic Living, Genomics, and the Quantified Self

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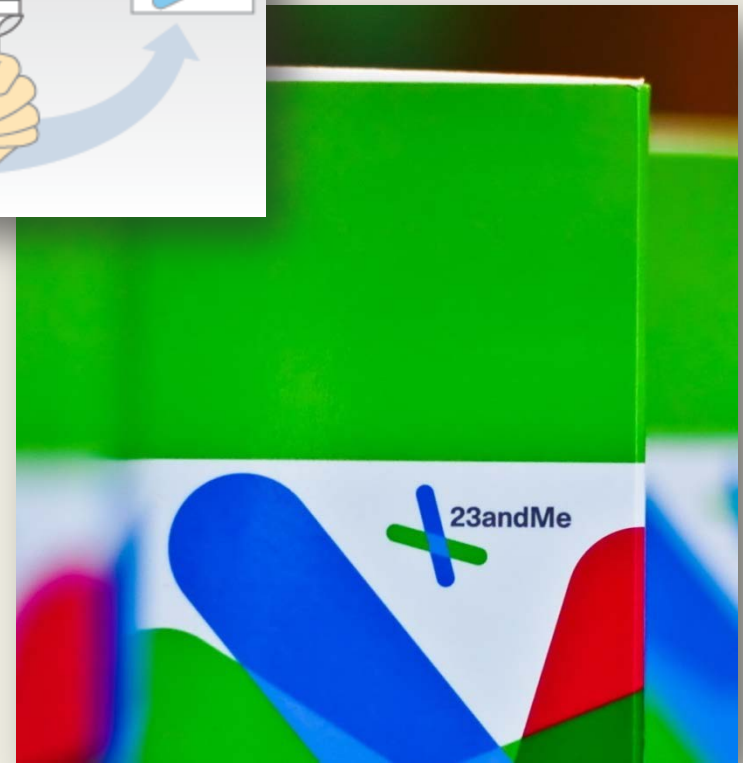
# Our Investigations

## 2 Ongoing Studies

- Genomics and the Quantified Self
  - Intel Science and Technology Center for Social Computing
  - socialcomputing.uci.edu
- Health Data Exploration
  - Robert Wood Johnson Foundation
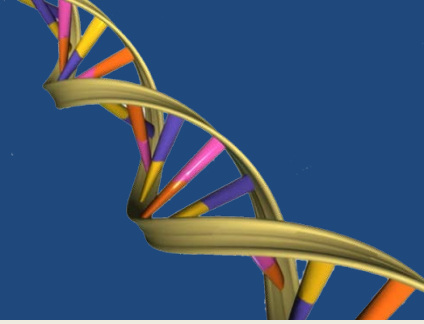  - www.calit2.net/hdexplore/

## Our Methods

- Surveys of QS behaviors and attitudes
- Interviews
- Discourse analysis
- Participant observation at QS events

# Personal Genetic Testing

- e.g. *23andMe*
  - $99
  - 240+ genetic disease and trait markers
  - 400,000+ genotyped customers

- Reports provide
  - Disease predictions
  - References to literature
  - Lifestyle advice
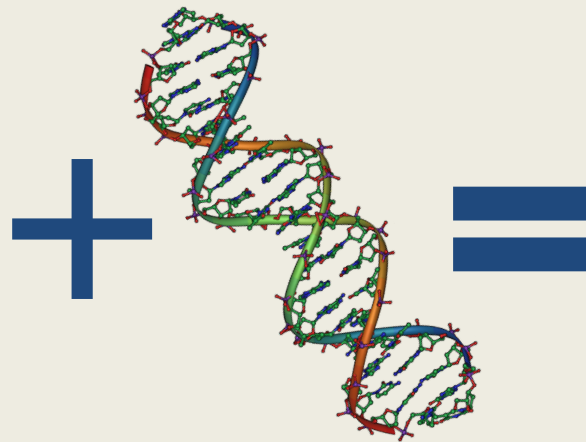  - Links to online communities
  - Ancestry information

# Personal Algorithmic Health
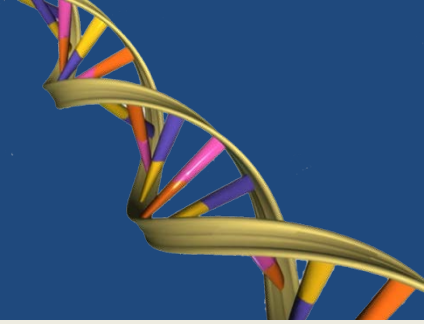
Lifestyle (Inputs)          DNA (Code)          Health & Happiness



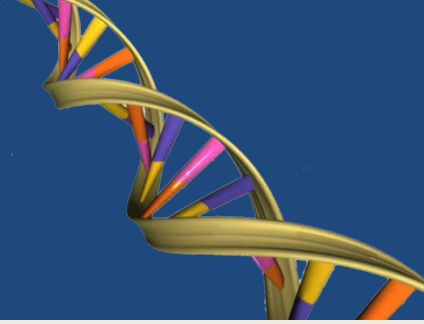**"Genetics loads the gun; lifestyle pulls the trigger."**

# Invisible Algorithms

- Testing is selective
  - e.g. BRCA and breast cancer
- Star ratings hide genetic complexity

| Elevated Risk | | |
| --- | --- | --- |
| Name | Confidence | Your Risk |
| Heart Attack | ★★★★☆ | 8.9% |

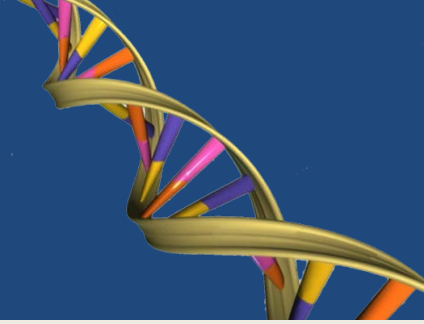- Black boxing open scientific controversies

# Genetic Ways of Knowing

- "By knowing your DNA, you can take steps toward living a healthier life." -23andme.com
- If genetic knowledge is important, what are we learning?
  - Sometimes what we already know
  - What is the "truth status" of genetic predictions?

| 99.9% | European |
|-------|----------|
| 0.1% | Unassigned |
| 100% | **Matthew Bietz** |

- Shifting toward a genetic epistemology
  - Ontic occlusion: How does this way of knowing block other forms of knowledge (Knobel, 2010)
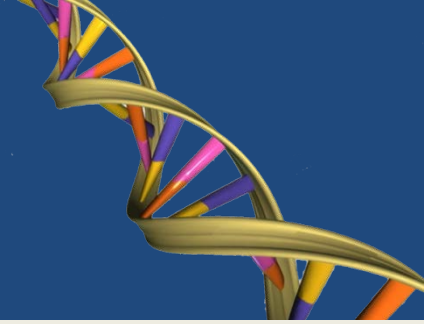
# Genetic Empowerment

"Understand your genetic risks. Change what you can, manage what you can't."

23andme.com

- Need a critical approach to genetic empowerment
  - Fear of genetic fate
  - "Do I want to know?"
- What role will personal genetics play in clinical dynamics?
- Material consequences of invisible algorithms

# The Genetic Self

- The self as algorithmic performance
  - "The more you know about your DNA, the more you know about yourself." -23andme.com
- I am my genome
  - Defined by genetic mutations
  - A collection of disease risk
- Membership in genetic communities
  - Family as genetic lineage
  - Biosociality: communities based on markers (Rabinow, 1992)

"Understanding our DNA can illuminate our lives in deep and impactful ways. Music reflects the uniqueness in each of us while simultaneously underlining the history and commonalities we all share."

-23andme.com

# Thank You!

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Health Data Exploration Project