

Week 9: Ethics

- logistics
- post
- ethics

Assignment 2: common themes/ advice for final report

- decisions made and defended
- cutoffs chosen & why
- number of SNPs/individuals included in analysis
- plots/tables should be included in final report
- does not just *have* to be PC1 and PC2

Assignment 3: Complete Project

- Report: start to finish explanation of what you did - the whys, hows, and what's should all be explained. Results should be in there along with interpretation and conclusion. This should use more data than just the test vcf.
- Code: should submitted run on the chr22 test vcf file and should adhere to all specifications discussed in methodology

Assignment 3: Grading (due: Sat 3/14)

- Code will be graded by Aaron
 - Will be run on DSMLP using the Dockerfile you specify
 - Data: Test file should be in your project directly
- Report: will be graded by me
 - Understanding by you demonstrated
 - Clear explanation of process
 - But best to make clear in your report what you did/how things work (will look at your code)
 - Results & Interpretation
 - Completeness (VCFs -> PCA) (good) vs demonstration of the entire pipeline (better)
 - Data to use: dsmlp for VCFs (more than just test file)

Group Proposals (next Wed)

- Question you want to address
- Brief introduction to the topic
 - i.e. intro to disease, intro to existing method/software, summary of previous research
- General Plan for next quarter (inc. possible datasets)
- Aim for ~7 min
- Everyone should speak
- Platform: Google Slides? no slides? Something else?

DSC180A: Overall Grading

- Assignments
 - Code + reports (1, 2)
 - Final report most important (code + report)
- Participation
 - Wednesdays in class
 - Domain office hours
 - Discussion Forms
- Proposal (Week 10)

Post-Assessment

18 questions; 12 minutes; Multiple Choice

How you do does not affect your grade

Only answer questions you have some idea about

Discussion Questions

Ethnicity Bias

- What bias exists in genetic studies? Why does this matter?
- If you were in charge at the NHGRI, what would you do to help solve this issue?

Bias

- Racial bias: mostly white individuals
- Other bias:
 - Sampling bias
 - Diseases studied
 - Who gets funding to do these studies
 - Who gets published
 - Where these studies get published
 - What news outlets report on

Proposed Solutions: Bias

*I would perform several studies across the world where continents are broken into **different regions** and each of those regions has their own study conducted on them.*

*If I were in charge I would obviously push for the inclusion of more diverse groups in genetic studies. I like the plan behind **All of Us** so I would put a lot of resources into it and eventually **expand it to include more than 1 million people**. There are so many different populations around the world and with time these efforts will hopefully prove successful in making genetic studies inclusive to all.*

*If I was in charge at the NHGRI, I would ask researchers to **purposely collect more data from minorities and females**. I would also encourage people to fund a campaign to allow more people to have their data collected.*

*I would make sure there is **funding specifically for each race, and encourage studies for less represented populations**. One movement is by the NIH which is to have a long-term diverse genetic study and **involve underrepresented populations**. Creating studies such as these will also help solve this issue, as more data will become readily available.*

Discussion Questions

Ethnicity Bias

- What bias exists in genetic studies? Why does this matter?
- If you were in charge at the NHGRI, what would you do to help solve this issue?

Who Owns Your Genetic Data

- Who could benefit/profit from having lots of genetic data? Who could be harmed?
- If you were in Congress, what would you do to protect against the mismanagement of genetic data?

Benefit & Harm

Benefit or profit: health insurance companies, physicians/hospitals, companies/businesses, recipients of precision medicine, scientists/geneticists/biologists, general population thanks to research,

Harmed: minority groups, individuals from groups not represented in scientific research, individuals whose genetic information is not protected (leaked, health insurance), those suffering from genetic diseases

Genetic Information Nondiscrimination Act (GINA)

- Written into law in 2008
- Prohibit unfair treatment based on DNA (genetic information)
- Applies to: employers & health insurance companies
- Does not apply to: life, disability, or long-term care insurance (some states have laws to take care of this)

Proposed Solutions: Protect Against mismanagement

*I would file a bill to **let each individual be the owner of its own genetic data**. Any companies need to get permission from you to access any information related to your genetic data.*

*This question is relatively tricky because I think it is **hard to ensure the protection of genetic data**. I don't think it is safe to allow private companies that are not under government regulations/affiliated with the government to have access to such data. I believe genetic data should be **treated more like a social security** and people should have the absolute right to choose when and how to share it. Ultimately, I would push for legislation that creates strict guidelines on the use of personal genetic data and **gives complete ownership to those who it belongs to**. However, then figuring out a secure solution to store such data will be difficult. **Having genetic data in a database may be too risky as it is vulnerable to bugs and hacking**.*

*Like stated in the article, I would ensure the **data stay in just one location** where it can be accessed on a permission-given-by-patient basis. Laws would need to pass to provide security for those who do have their genome information out in the world. No big corporations would be allowed access due to foreseen biases.*

Discussion

Solution to racial bias: Collect more data from individuals not represented

Benefit/Harm: Genetic data can be used to harm individuals

Student Questions: Privacy

How is ownership of genetic data handled/thought of differently, if at all, from ownership of financial data (credit card information, bank statement, etc) and other types of data?

Data privacy has become a larger problem. How do [we] formally define the border line is getting harder?

(Important, Existential) Student Question

From the VOX article, I keep wondering if our future will be like the one in Gattaca, where people simply pay for choosing the optimal genes for their babies. It sounds really scary to me because by then humans will play the role of God. Even it does become reality, how to simply switch the genes? Using CRISPR?