Modern computing and personal genotyping:
THE ETHICS OF GENOMICS

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What is genomics?

▸ Benefits of genomics (preventive medicine and pharmacogenomics)

Computing and Genomics

- Computing Power and Genomic Sequencing
- Sequencing Human Genome
  - Around 750 Megabytes
  - Human Genome Project took 8 years (1995-2003)
  - Most commercial companies take 2 days now
- Commercialization
  - Personal sequencing services
  - Personal sequencers
- But, analyzing takes more computing power!
  - Supercomputers in bioinformatics
  - High cost of infrastructure
    - Traditional supercomputer vs. distributed systems (farms)

Growing Role of Software

- Software issues in Bioinformatics Infrastructure
  - "Cloud" and distributed computing systems
    - Queueing
    - Data distribution
    - Networking
    - Logging and hardware/software failure
- Software in the Future Bioinformatics
  - In-house software vs. third-party software
    - Licensing the in-house software
  - Security
    - Genomics data are beginning to be stored in web servers

Reprogenetics

- Preimplantation Genetic Diagnosis (PGD)
  - high rate of success in analyzing and determining the genetic content of gametes
- "Designer Babies"
  - can currently identify gender chromosomes and a dozen or so X-linked genetic disorders (Fragile X Syndrome, Duchenne muscular dystropy)
- Ethical Issues

Privacy: A traditional take

- Medical records pass through many hands within an organization

- WHO recommends:

  World Health Organization

  - Show-and-tell information to be shared with patients

  - No details over shared phone, fax, email, or by postcard

  - Not to store data on shared computers

  - Restricting info to patient and those granted access

  - Data handling by select individuals only

Privacy: A more modern view

- 23andMe removes middle-man i.e. the clinic

- Data is available via the web

- Data is protected by a simple email and password

- Susceptibility to social engineering attacks and hacking

- 23andMe maintains that protecting personal information is a shared responsibility
  - users must safeguard passwords, secret questions
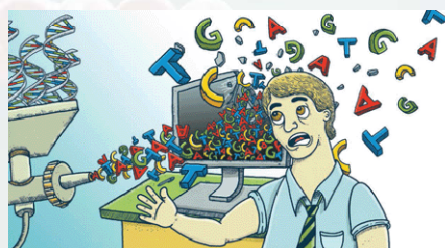
Privacy: Behind the scenes

- Costs of sequencing are decreasing
- Cloud providers increasingly used for computation and data storage
- Cloud providers reduce cost and offer centralized repository of public genetic archives
- Shared data storage and virtual systems are less secure
- Security not a top priority for cloud providers
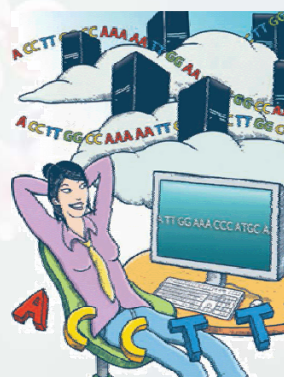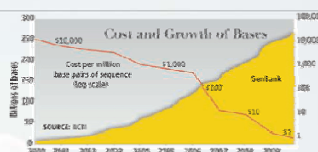
GINA

- Genetic Information Nondiscrimination Act
- Prohibits:
  - Discrimination in health insurance and employment decisions
  - Looking at genetic information before enrollment
  - Requiring genetic testing
  - Changing cost or coverage after testing
- Excludes:
  - Life and disability insurance

Conclusion

For further information, visit:
http://stanford.edu/~bocon/cs181/