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Ancestry and Privacy: It’s all relative.

Genetic Alliance Privacy and Progress Webinar Series “Ancestry and WGS: Other Privacy Concerns?”
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Overview

• Ancestry Tests
• Privacy and confidentiality
• Legal Perspective on Privacy Rights
• Whose privacy interests?
• Privacy or Something Else?
We all share common ancestry

“...I note the obvious differences between each sort and type, but we are more alike, my friends than we are unalike...”
~ Excerpt from Maya Angelou’s *The Human Family*

- Continental and Biogeographical Ancestry
- Descent Groups, Clans, and Lineages
- Sociopolitical rules
  - Unilineal, ambilineal, and bilateral descent
  - Hypodescent and Hyperdescent rules

Image taken from Royal et al. 2010. Inferring Genetic Ancestry: Opportunities, Challenges, and Implications. *Am J Hum Genet* 86: 661-673 (Figure 1, at 664)
Genealogies, Pedigrees, & Family Histories

• Relatives
  – Consanguinal (“blood issue”)
    • Lineal
    • Collateral
  – Affinal

• Family
  – Family of Orientation
  – Family of Procreation

• Kin

• Genealogical Ancestry
  – *Expected* levels of shared biological ancestry

• Genetic/omic Ancestry
  – *Realized* (or *measured*) levels of shared biological ancestry
“Today we inhabit a legal regime that is the accretion of centuries of myth and amnesia.” ~ Daniel Sharfstein

<table>
<thead>
<tr>
<th>Hypodescent</th>
<th>Hyperdescent</th>
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<td>• The child of parents of different ethnicities or races will be determined by assigning the child to the ethnicity or race of the more socially subordinate* parent.</td>
<td>• The child of parents of different ethnicities or races will be determined by assigning the child to the ethnicity or race of the more socially dominant* parent.</td>
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<td>• Example: One-drop rule, Virginia Racial Purity Act 1924</td>
<td>• Example: blood quantum rules, 1934 Indian Reorganization Act</td>
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For more information, read Ian Haney-Lopez, White by Law: The Legal Construction of Race
Are researchers and participants or companies and consumers speaking the same language?

Privacy ≠ Confidentiality

- **Privacy**
  - relates to a person, controlling access to one’s self.

- **Confidentiality**
  - relates to treatment of data or information shared from one person to another in a particular fiduciary relationship, *e.g.*, 
    - attorney-client,
    - physician-patient,
    - researcher-research participant,
    - priest-penitent, and
    - spouse-spouse

See, *e.g.*, [http://research.uci.edu/ora/hrpp/privacyAndConfidentiality.htm#privacy](http://research.uci.edu/ora/hrpp/privacyAndConfidentiality.htm#privacy)
Privacy Rights in the US

• *The Warren & Brandeis Article*
  – Famous 1890 argument urged judicial recognition of a common law right to privacy.
  – Privacy is a principle of “inviolate personalty”

• Constitutional Basis for Protecting Privacy
  – First Amendment
    • Freedom of Expression & Association
  – Fourth Amendment
    • Search & Seizure protections
  – Fifth or Fourteenth Amendment
    • Due Process protections

• Four Realms of Privacy Law
  – Informational privacy
  – Physical privacy
  – Decisional privacy
  – Proprietary privacy
Legal Perspective on Privacy

• **Four Realms of Privacy**
  – Informational
  – Physical
  – Decisional
  – Proprietary

• **Civil Complaints for Invasion of Privacy**
  – Intrusion Upon Seclusion
  – Public Disclosure of Private Facts
  – False Light
  – Appropriation
Surreptitious Testing

• A party (other than law enforcement) ordering or performing a genetic test or analysis on DNA samples of another without their knowledge or consent.
  – Examples:
    • spit from a cigarette butt, chewing gum, or soda can or hair from a brush to test identity, paternity, or other relationships;
    • clothing of a distrusted partner to test fidelity;

• Banned in the UK since 2006 (Human Tissue Act of 2004)

Image from http://www.abajournal.com/magazine/article/gene_swipe_few_dna_labs_know_whether_chromosomes_are_yours_or_if_you_stole_/
There is no specifically recognized federal right to “genetic privacy” in the US yet.

Image from http://www.geneticsandsociety.org/img/original/biobank-privacy_1.jpg
A Glimpse at the States

Comprehensive
Limited
None on point

Image adapted from “Privacy and Progress in Whole Genome Sequencing.” Presidential Commission for the Study of Bioethical Issues (October 2012) P. 121.
Federal law establishes the floor, not the ceiling.

Plus a patchwork of:
- Specific state statutes
- Generally applicable federal laws
- Generally applicable state laws

In the US, privacy of personal information is addressed contextually rather than with one universally applicable privacy law.

Figure from “Privacy and Progress in Whole Genome Sequencing.” Presidential Commission for the Study of Bioethical Issues (October 2012) P. 61.
Privacy interests of whom?

- Individual Consumer/Participant/Patient
- Relatives (as individuals)
- Family (as an collective entity or unit)
- Community
- Ethnic Group
- Population
Informed Consent = A Waiver of Privacy

• But consent from whom?
  – An individual
  – A group of individuals
  – An entire group as a collective entity

• If an individual, which individual(s)?
  – The one from whom a biospecimen (cheek swab, saliva, blood sample, saliva) can be obtained?
  – The many about whom the information relates in probabilistic ways?

“Relative Futility” (Woodage, 2010)
Sources of Ancestry Information

- Informants (known and unknown)
- Vital Records (birth, death, marriage, etc.)
- Public Information (newspapers, digital archives)
- DNA tests

Interests of “root-seeker” to access information may be in conflict with privacy interests of those sought.
Each genomic locus has its own evolutionary past.

Different DNA ancestry tests have potential to reveal different information (because they assay different loci) and information about different individuals (because they assay types of loci inherited uni-parentally or bi-parentally).

Beware of genetic determinism & non-distributive generalizations.
Overarching Goal: Protecting Privacy or something else?

- Other Concerns
  - Commodification
  - Exploitation
  - Stigmatization
  - Discrimination
  - Cultural Harms
  - Genetic Stalking
  - “re-identification” risks

- Case Studies
  - Genetic Research and the resulting dispute between Havasupai Tribe and Arizona State University scientists
    - See Vorhaus, Genomics Law Report, April 21, 2010
  - Development of special rules for genomic research involving HeLa cell lines.
    - See Wagner, Genomics Law Report, August 27, 2013
DNA Ancestry & Identity

- **Objective self-fashioning**

- **Affiliative self-fashioning**

- A “double entendre of recreation and recreation…” (Lee, 2013)
- “ethnostress” (Cajete, 1994)
- “ethnic options” (Waters, 2001)
Closing Remarks

- Privacy interests are relative and often competing with other interests.
  - E.g., An individual’s right to access information about himself/herself vs. other individuals’ rights to restrict access to information about themselves.

- Privacy interests are variable. There is inter- and intra-individual, temporal, and spatial variability.
  - E.g., privacy of information about living vs. deceased persons
  - Adoptees and children of assisted reproductive technologies
  - Missing persons
  - Trafficked persons

- Sociotechnical architecture affects experiences, attitudes, and awareness (as well as ability to control the flow of information).

- In shaping our genetic rights, we must consider policies not only focused on privacy but also other interests, such as non-discrimination and equality.
Suggested Reading