Consumer Genomics Testing: Regulatory and Health Policy Issues

Amy McGuire, JD, PhD
Center for Medical Ethics and Health Policy
Baylor College of Medicine
Session Objectives

Address data sharing, privacy, and security issues in the context of consumer genomics testing

Explore the landscape of emerging regulatory issues in consumer genomics
How is Sally’s Data Protected?

TERMS OF SERVICE

FEDERAL TRADE COMMISSION
Free publications for America’s consumers
With whom might Sally’s data be shared?
Prevent unauthorized access in Research and Clinical Care
Protect against discriminatory use
Law Enforcement Access to Consumer Genomic Information
Whose privacy are we worried about?
### Match #1

<table>
<thead>
<tr>
<th>Chr</th>
<th>Start Location</th>
<th>End Location</th>
<th>Centimorgans (cM)</th>
<th>SNPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>36,495</td>
<td>5,800,005</td>
<td>17.6</td>
<td>2,345</td>
</tr>
<tr>
<td>3</td>
<td>67,728,488</td>
<td>199,310,226</td>
<td>132.1</td>
<td>26,449</td>
</tr>
</tbody>
</table>

### Match #2

<table>
<thead>
<tr>
<th>Chr</th>
<th>Start Location</th>
<th>End Location</th>
<th>Centimorgans (cM)</th>
<th>SNPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>36,495</td>
<td>5,168,135</td>
<td>15.8</td>
<td>2,114</td>
</tr>
<tr>
<td>3</td>
<td>104,270,146</td>
<td>168,695,458</td>
<td>57.2</td>
<td>13,878</td>
</tr>
</tbody>
</table>

### Match #3

<table>
<thead>
<tr>
<th>Chr</th>
<th>Start Location</th>
<th>End Location</th>
<th>Centimorgans (cM)</th>
<th>SNPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>104,090,483</td>
<td>114,098,727</td>
<td>7.4</td>
<td>2,130</td>
</tr>
</tbody>
</table>
Max Persons of Interest tested in 4 cases as a result of IGG

Max Persons of Interest tested in same 4 cases prior to IGG (as a result of other leads)

*Confidential source*
It’s all about trade-offs
Thank you
Diversity of Opinion on Appropriate Response

Is it time for a universal genetic forensic database?

J. W. Hazel, E. W. Clayton, B. A. Malin, C. Slobogin

+ See all authors and affiliations

Science 23 Nov 2018:
DOI: 10.1126/science.aav5475
Most White Americans’ DNA Can Be Identified Through Genealogy Databases

Only two percent of the population needs to have done a DNA test to identify nearly everyone else, researchers found. Leonard Lessin/Science Source
1. Collect crime scene sample
2. Exhaust investigative leads
3. Develop SNP profile of person of interest (POI) from crime scene sample
4. Upload SNP profile to genetic genealogy (GG) database
5. Search SNP profile against other profiles in GG database
6. Based on relative matches resulting from search, develop family tree for POI
7. Research persons on tree and develop leads to identify POI
8. Arrest POI if DNA matches DNA from crime scene sample

*Meredith Trejo*
Are people like Sally concerned with their privacy?

Younger Millennials (n=418) 18-28 years
Older Millennials (n=354) 29-35 years
Generation X (n=348) 36-51 years
Baby Boomers (n=190) 52-70 years

MTurk Survey 2016 (n=1310)

Privacy of Health Information:
- Younger Millennials: 58%
- Older Millennials: 73%
- Generation X: 71%
- Baby Boomers: 74%

Privacy of Online Information:
- Younger Millennials: 66%
- Older Millennials: 65%
- Generation X: 71%
- Baby Boomers: 71%

Social media use not a predictor of concern

69% concerned
It’s all about trade-offs