INSIDE the CELL

The Dark Side of Forensic DNA

ERIN E. MURPHY

FORENSIC INVESTIGATIVE GENETIC GENEALOGY (FIGG)

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- **FIGG IS NEW.** Genetic Genealogy is not just forensic DNA plus, but something totally different.

- **THE RISKS ARE AS REAL AS THE BENEFITS.** These are real, not just hypothetical, dangers in allowing the government (and private citizens) unfettered access to people’s genomes.

- **REAL CONSTRAINTS AND OVERSIGHT, WITH INPUT FROM BROAD STAKEHOLDERS, IS IMPERATIVE.** Existing regulatory structures, including self-monitoring, are insufficient. We need new, robust, and independent training, oversight, transparency, and accountability mechanisms – bringing in not just law enforcement and legal system stakeholders but experts in health research, racial justice, medical ethics, consumer privacy, clinical QA/QC, etc.
<table>
<thead>
<tr>
<th>Traditional forensic DNA/CODIS system</th>
<th>Genetic Genealogy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Test type</strong></td>
<td></td>
</tr>
<tr>
<td>• Non-coding, &quot;junk&quot; STR, ~20 loci loci (~10,000 bp of repeats)</td>
<td>• SNP, “gold,” panels developed for biomedical research, ~600k to 1 million nucleotides (GTCA)</td>
</tr>
<tr>
<td><strong>Analysis done by</strong></td>
<td></td>
</tr>
<tr>
<td>• Government analysts in regulated government labs, or outsourced labs compliant with QAS</td>
<td>• Largely unregulated private, for-profit companies; private persons</td>
</tr>
<tr>
<td><strong>Sample restrictions</strong></td>
<td></td>
</tr>
<tr>
<td>• Source: putative perpetrator crime scene sample (no victims, clear non-suspects, non crime-scene evidence)</td>
<td>• Site, vendor dependent; possibly none</td>
</tr>
<tr>
<td>• Quality: 8+ loci + rarity; single source or deconvolved or mixture under 4 alleles/loci</td>
<td></td>
</tr>
<tr>
<td>• Kits: validated &amp; standardized &quot;profile&quot;</td>
<td></td>
</tr>
<tr>
<td>• Kits: validated within laboratory</td>
<td></td>
</tr>
<tr>
<td>• Lab/analyst: CODIS QA/QC, including accreditation</td>
<td></td>
</tr>
<tr>
<td><strong>Data storage</strong></td>
<td></td>
</tr>
<tr>
<td>• Paperwork/documentation required</td>
<td>• Site, vendor, genealogist dependent; possibly none</td>
</tr>
<tr>
<td>• Audits for accuracy</td>
<td></td>
</tr>
<tr>
<td>• No national storage of elimination samples, witnesses, or non-perpetrators</td>
<td></td>
</tr>
<tr>
<td>• Decentralized data; pointer system</td>
<td></td>
</tr>
<tr>
<td><strong>Search restrictions</strong></td>
<td></td>
</tr>
<tr>
<td>• Access limited to pre-qualified personnel</td>
<td>• Site, vendor, genealogist dependent and self-enforced by genealogists; possibly none</td>
</tr>
<tr>
<td>• Criminal penalties for misuse</td>
<td></td>
</tr>
<tr>
<td><strong>Privacy of target AND non-target others</strong></td>
<td></td>
</tr>
<tr>
<td>• Weak ancestral, 1st degree relatives</td>
<td>• Biomedical information; possibly behavioral info</td>
</tr>
<tr>
<td></td>
<td>• Detailed ancestral; links to thousands well beyond social family</td>
</tr>
<tr>
<td></td>
<td>• Implicates ancestors and descendants</td>
</tr>
</tbody>
</table>
What other crime scene evidence is as...

- **EVOLVING**: Not limited to informational value at the moment of seizure, but revelatory about the past (prior generations) and future (unborn descendants) and continues to gain capacity to reveal sensitive information.

- **IMMUTABLE**: If obtained by bad actors or misuse is feared, can’t just revoke or “reissue” your (or your descendants’) DNA.

- **MONETIZABLE**: Has tremendous value outside of crime-solving.
Pentagon Leaders Tell Troops to Stop Using Mail-In Genealogy DNA Kits

In a way of explanation for the new order, the memo states, “These [direct-to-consumer] genetic tests are largely unregulated and could expose personal and genetic information, and potentially create unintended security consequences and increased risk to the joint force and mission.” Inaccurate ancestry DNA testing by unsecured companies is the worry of the DoD.

Consumer privacy advocates argue that there need to be more regulations to limit the use of genetic information by insurance companies in order to protect privacy and prevent discrimination.

“There’s probably nothing more personal than your genetic information,” says Susan Grant, director of consumer protection and privacy at the Consumer Federation of America. “Of all the kinds of sensitive data there may be about people, that’s right up at the top of the list.”

The insurance industry, on the other hand, claims that consumers benefit when insurers have this information.
• Wrongful arrest & detention (and even conviction)

• Overbroad & intrusive investigations, with a lack of accountability (and incentives to break rules and push ethical boundaries)

• Spillover effects: undermining community trust and public health benefits of DNA, especially for communities of color
United States v. Weikert, 504 F.3d 1 (1st Cir. 2007): “Weikert's argument [is that ] the government might disregard its current stated procedure of using only the specified section of junk DNA to create an identifying profile, and might instead examine other sections of his DNA to extract personal information [such as “information about his daughter, his parents, his other family members [or] about diseases, environmental predispositions, or recessive traits]…. We emphasize that other factors, such as demonstrated misuse of the DNA samples, a change in the government's collection procedures to include non-junk DNA, or the discovery of new uses for “junk DNA” would require a reevaluation of the reasonableness balance”

U.S. v. Mitchell, 652 F.3d 387 (3d Cir. 2011): Should technological advancements change the value of “junk DNA,” reconsideration of our Fourth Amendment analysis may be appropriate.”

United States v. Kriesel, 720 F.3d 1137 (9th Cir. 2013): We have previously stressed that if scientific discoveries make clear that junk DNA reveals more about individuals than we have previously understood, we should reconsider the government's DNA collection programs.

Haskell v. Harris, 669 F.3d 1049 (9th Cir. 2012): If we were addressing a legislative scheme in which the Government could freely use a person's DNA sample in any manner and for any purpose, serious privacy interests could be at stake. But we are not presented with an open-ended legislative scheme in which citizens' entire genomes are placed on file with the Government.

United States v. Amerson, 483 F.3d 73 (2d Cir. 2007): We are mindful of the vast amount of sensitive information that can be mined from a person’s DNA and the very strong privacy interests that all individuals have in this information…Should the uses to which “junk DNA” can be put be shown in the future to be significantly greater than the record before us today suggests, a reconsideration of the reasonableness balance struck would be necessary.”
WASHINGTON STATE MAN RELEASED AS COLD-CASE MURDER SUSPECT SUES DETECTIVE

3.10 In between the date of Plaintiff’s arrest, on April 28, 2019, and his release on November 30, 2022, Plaintiff’s life was destroyed, and he suffered severe emotional distress and trauma. He lost everything that was important to him: his job, his friends, and his home. During Plaintiff’s time in custody, Plaintiff’s wife was terminally ill. Plaintiff’s attempts to see and hold his wife prior to her death were denied in a two-sentence order. She passed in June 2021 while Plaintiff sat in Clark County Jail awaiting trial. And while Plaintiff welcomed his freedom, the Prosecution’s dismissal has not removed the cloud of suspicion that remains over Plaintiff to this day.

A Washington man who was jailed for three years on charges accusing him of the 1994 cold-case rape and murder of a Vancouver, Clark County, woman — only to have the case dismissed — has sued the detective who accused him, alleging he “made deliberately false statements” and acted “with reckless disregard for the truth.”


Frasier, who lived with her 5-year-old son, had been strangled and sexually assaulted, according to police and prosecutors.

The complaint alleges the charges relied entirely on the same “cutting-edge” genealogical technology used to track the infamous Golden State Killer and touted as a powerful tool to identify unknown subjects using DNA testing, high-speed computers and family history.

Investigators collected multiple DNA samples from the scene of Frasier’s homicide, but none matched their initial suspects. The Police Department also submitted the samples to a national database but came up empty, according to the charges and news reports.

According to news reports, Goudschaal and another detective then sent the DNA evidence to Parabon Laboratories, a Virginia-based company that specializes in DNA profiling for law enforcement.

Clark County prosecutors initially embraced the investigation, charging and arresting Knapp in April 2019, hailing the advantages and success of the new technology and investigation techniques.

Then, in 2022 — with much less fanfare — prosecutors dropped the charges against Knapp, who had been held for three years on $1 million bail and now appears to have been falsely accused, stating the office “was no longer convinced beyond a reasonable doubt, based on the evidence we have as we understand it now, that Mr. Knapp could be convicted.”
*2 At the time of Mr. Monteiro's arrest, he was married and had four children. As a result of the publicity accusing him of Christine's murder, Mr. Monteiro alleges that he lost his job despite his tenure of 15 years with a single employer and has not been able to work since. He has reported that he became homeless. According to a declaration from his sister, he became a recluse in the wake of the publicity identifying him as a child murderer. (ECF No. 50-56.)
The field of forensic DNA analysis is constantly advancing. One important change involves the ability to detect and analyze very small quantities of DNA (Butler 2012, Butler 2015a). During the early decades of forensic DNA analysis, an evidence sample containing thousands of cells, such as a visible blood or semen stain, was needed to produce a DNA profile. Today, analysts can extract a DNA profile from the few skin cells that someone might leave behind when handling an object.

Distinguishing one person’s DNA from another in these mixtures, estimating how many individuals contributed DNA, determining whether the DNA is even relevant or is from contamination, or whether there is a trace amount of suspect or victim DNA make DNA mixtures inherently more challenging to interpret than single-source samples. These issues, if not properly considered and communicated, can lead to misunderstanding the strength and relevance of the DNA evidence in a case.

When laboratories analyze high-quality, single-source samples, decision-makers often have confidence in DNA test results in part because it has been demonstrated that different laboratories will arrive at the same result; that is, obtain the same DNA profile at the tested loci. This is regardless of the specific instruments, kits, and software used. However, multiple interlaboratory studies conducted by different groups over the past two decades have demonstrated a wide range of variation in how specific DNA mixtures are interpreted (Duewer et al. 2001, Crespillo et al. 2014, Benschop et al. 2017a, Barrio et al. 2018, Butler et
Colorado’s Star DNA Analyst Intentionally Manipulated Data, Investigation Finds

Yvonne “Missy” Woods allegedly cut corners and violated policies for years, affecting more than 650 cases

By Dan Frosch Follow
March 8, 2024 2:07 pm ET

Colorado’s star DNA scientist intentionally manipulated evidence for years, calling into question all of the criminal cases she worked on in her nearly three-decade career, according to a preliminary investigation released by officials Friday.

Yvonne “Missy” Woods, who helped solve some of the state’s most notorious crimes, abruptly left her post last November after the Colorado Bureau of Investigation discovered anomalies in her work and initiated a criminal probe. The internal inquiry released Friday asserts that Woods, long one of the bureau’s most respected analysts, purposefully altered DNA testing results.

The report said her manipulation affected at least 652 cases she handled between 2008 and 2023. The total could end up being higher, as investigators are still reviewing Woods’s cases dating back to the beginning of her career in 1994.
Framed for Murder By His Own DNA

When the DNA results came back, even Lukis Anderson thought he might have committed the murder.

"I drink a lot," he remembers telling public defender Kelley Kulick as they sat in a plain interview room at the Santa Clara County, California, jail. Sometimes he blacked out, so it was possible he did something he didn't remember. "Maybe I did do it."

They were Anderson’s medical records. Because his murder charge could carry the death penalty, Kulick had the investigator pull everything pertinent to Anderson’s medical history, including his mental health, in case they had to ask for leniency during sentencing.

What happened, although months would pass before anyone figured it out, was that Lukis Anderson's DNA had found its way onto the fingernails of a dead man he had never even met.

Kulick remembers turning to the investigator, who was staring back at her. She was used to alibis being partial and difficult to prove. This one was signed by hospital staff. More than anything, she felt terrified. "To know that..."
• Wrongful arrest & detention (and even conviction)

• Overbroad & intrusive investigations, with a lack of accountability (and incentives to break rules and push ethical boundaries)

• Spillover effects: Undermining public health benefits of DNA generally, especially for communities of color
Could law enforcement...

- GG for non-homicide/rape crimes?
- Pretextual offenses?
- Go beyond agreed terms of service or fake identity to get access to non-LE data?
- Access profiles that haven’t agreed to LE access?
- Issue subpoena or get court order for GG search of closed commercial databases like 23andMe?
- GG to find an eyewitness, a reluctant victim (e.g., rape)?
- Set up fake accounts to mine for data
- Upload fake samples in attempt to ascertain the profiles of people they know are in the database? (“reverse search”)
- Surreptitiously sample persons known not to be suspects, to aid investigation?
- Surreptitiously sample a large number of potential targets in order to speed up investigation?
- Retain surreptitious samples and profiles in a rogue LE databases?
- Retain elaborate family trees in LE databases?
- Retain intimate data on uncontrolled laptops etc. (birth, death, financial, marriage, immigration, adoption, religious, educational records etc.)
- Disclose incidental findings, whether for LE purpose or some other reason (e.g., alert family member of treatable genetic condition, threaten family member with exposing illegitimate child if don’t cooperate)?

The risks are as real as the benefits.
Could law enforcement...already have

- GG for non-homicide/rape crimes?
- Pretextual offenses?
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The risks are as real as the benefits.
OUR COMMITMENT

We won’t share your DNA

We believe your DNA belongs to YOU and only you ... period. For that reason, we will never sell your DNA to third parties.

Can the other guys say that?

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FamilyTreeDNA Admits to Sharing Genetic Data With F.B.I.

FamilyTreeDNA, an at-home DNA testing company, apologized for failing to disclose it was sharing genetic information with the F.B.I. to help solve rapes and murders. Some of the site's users felt the company had betrayed them.

By Matthew Haag

Feb. 6, 2016

The Future of Privacy Forum, along with leading consumer genetic and personal genomics testing companies 23andMe, Ancestry, Helix, MyHeritage, and Habit, released Privacy Best Practices for Consumer Genetic Testing Services. These companies have been joined by African Ancestry, FamilyTreeDNA,* and Living DNA in supporting the Best Practices as a clear articulation of how testing firms can build trust with consumers.

*In January 2019, Family Tree DNA revealed an agreement with the FBI that conflicts with FPP’s Best Practices. FPP immediately removed Family Tree DNA as a supporter.
The Arrest Of A Teen On An Assault Charge Has Sparked New Privacy Fears About DNA Sleuthing

Critics fear we’re on a slippery slope of genetic genealogy being used to investigate less serious crimes. “We’re right here on the precipice, sliding down,” one expert said.
‘Game-Changer’ Warrant Let Detective Search Genetic Database

Privacy experts say it could set a precedent, opening up all consumer DNA sites to law enforcement agencies across the country.

Ancestry says it fought two police requests to search its DNA database

It’s not the first time Ancestry has pushed back against a legal demand. Last year the company said it rejected an out-of-state search warrant, ordered by a court in Pennsylvania, to “seek access” to its DNA database on the grounds that the warrant was “improperly served.”

Ancestry has only complied with one search warrant for DNA data from a database it acquired and later made public, not realizing that police would use the database to search for leads.

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>DATA REQUESTS RECEIVED</th>
<th>NUMBER OF USERS / ACCOUNTS SPECIFIED</th>
<th>DATA PRODUCED (BY USER ACCOUNT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL</td>
<td>11</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>United States</td>
<td>11</td>
<td>15</td>
<td>9</td>
</tr>
</tbody>
</table>
THE RISKS ARE AS REAL AS THE BENEFITS

POLICE ARE GETTING DNA DATA FROM PEOPLE WHO THINK THEY OPTED OUT

Forensic genetic genealogists skirted GEDmatch privacy rules by searching users who explicitly opted out of sharing DNA with law enforcement.

The loophole, which a source demonstrated for The Intercept, allows genealogists working with police to manipulate search fields within a DNA comparison tool to trick the system into showing opted-out profiles. In records of communications reviewed by The Intercept, Moore and two other forensic genetic genealogists discussed the loophole and how to trigger it. In a separate communication, one of the genealogists described hiding the fact that her organization had made an identification using an opted-out profile.

Roy, playing the part of opposing counsel, was pointed in her cross-examination: Was Binder aware of the GEDmatch loophole? And had she used it? Yes, Binder said. “How many times?” Roy asked.

“A handful,” Binder replied. “Maybe up to a dozen.”

Despite those words of caution, Moore is one of several high-profile genetic genealogists who exploited a loophole in a commercial database called GEDmatch, allowing them to search the DNA of individuals who explicitly opted out of sharing their genetic information with police.
SCOURING RECORDS THAT LINK PEOPLE BIOLOGICALLY, NOT SOCIALLY, REVEALS:

• secret relationships
• health trends (e.g., lung cancer runs in the family)
• longevity and chronic illness
• fertility trends (maternal age at birth, miscarriages, multiple partners, assisted reproduction)
• political or religious affiliations
• residential stability
• financial stability
• educational attainment trends
• social identities

Moore’s team and IFPD investigators utilized other information, such as age, location, triangulation between matches, and/or ancestry and phenotype (trait) predictions, to narrow down the possibilities before a final list of six possible leads was produced. The science showed that DNA collected from just one of the individuals on this list, even if it wasn’t a match to the DNA at the 1996 crime scene, would lead to the further identification of the suspect DNA.

IFPD set out to collect a DNA sample from one of these six people—people who were spread out around the country. While IFPD was fully prepared to send the entire team of detectives to different states if needed and had plans in place to do so, the closest lead was living in Twin Falls, Idaho. In February, IFPD investigators took a team of detectives to Twin Falls to hunt for DNA.
UNITED STATES DEPARTMENT OF JUSTICE
INTERIM POLICY
FORENSIC GENETIC GENEALOGICAL DNA ANALYSIS AND SEARCHING

In certain cases, the genetic association of an FGG profile with a GG service user, in conjunction with subsequent genealogy research, may identify one or more third parties who may have a closer kinship relationship to the donor of the forensic sample than the associated GG service user. In such cases, the acquisition of reference samples from these third parties for the purpose of conducting FGGS may help the investigative agency identify the donor of the forensic sample.

An investigative agency must seek informed consent from third parties before collecting reference samples that will be used for FGGS, unless it concludes that case-specific circumstances provide reasonable grounds to believe that this request would compromise the integrity of the investigation. If that determination is made, the investigative agency shall consult with, and receive approval from, the prosecutor before covertly collecting any reference samples that will be used for FGGS. The investigative agency shall also consult with the DLO, who may provide guidance to investigators about the type and nature of biological samples that may prove most conducive to FGG analysis. Covert collection shall be conducted in a lawful manner. In addition, a search warrant shall be obtained by the investigative agency before a vendor laboratory conducts FGG analysis on any covertly-collected reference sample.
• Wrongful arrest & detention (and even conviction)

• Overbroad & intrusive investigations, with a lack of accountability (and incentives to break rules and push ethical boundaries)

• Spillover effects: Undermining public health benefits of DNA generally, especially for communities of color
<table>
<thead>
<tr>
<th>Period</th>
<th>Total</th>
<th>Violent</th>
<th>Property</th>
<th>Homicide</th>
<th>Rape</th>
<th>Robbery</th>
<th>Assault</th>
<th>Burglary</th>
<th>Vehicle theft</th>
<th>Larceny/ theft</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990-94</td>
<td>21.0%</td>
<td>46.4%</td>
<td>16.1%</td>
<td>58.2%</td>
<td>52.5%</td>
<td>24.2%</td>
<td>59.8%</td>
<td>12.8%</td>
<td>10.9%</td>
<td>19.2%</td>
</tr>
<tr>
<td>1995-99</td>
<td>20.8%</td>
<td>49.4%</td>
<td>15.1%</td>
<td>59.0%</td>
<td>49.5%</td>
<td>25.6%</td>
<td>61.0%</td>
<td>12.9%</td>
<td>10.1%</td>
<td>17.4%</td>
</tr>
<tr>
<td>2000-04</td>
<td>18.6%</td>
<td>47.1%</td>
<td>13.5%</td>
<td>53.7%</td>
<td>45.4%</td>
<td>25.3%</td>
<td>57.6%</td>
<td>12.6%</td>
<td>9.6%</td>
<td>15.0%</td>
</tr>
<tr>
<td>2005-09</td>
<td>17.8%</td>
<td>42.8%</td>
<td>13.6%</td>
<td>55.2%</td>
<td>42.8%</td>
<td>25.3%</td>
<td>52.8%</td>
<td>12.8%</td>
<td>8.6%</td>
<td>15.4%</td>
</tr>
<tr>
<td>2010-14</td>
<td>18.0%</td>
<td>44.6%</td>
<td>13.8%</td>
<td>63.0%</td>
<td>41.5%</td>
<td>28.0%</td>
<td>54.2%</td>
<td>13.0%</td>
<td>7.5%</td>
<td>15.7%</td>
</tr>
<tr>
<td>2015-19</td>
<td>16.3%</td>
<td>45.2%</td>
<td>11.1%</td>
<td>62.4%</td>
<td>37.7%</td>
<td>30.8%</td>
<td>53.5%</td>
<td>11.0%</td>
<td>9.1%</td>
<td>11.7%</td>
</tr>
<tr>
<td>2020</td>
<td>15.4%</td>
<td>45.2%</td>
<td>9.3%</td>
<td>58.9%</td>
<td>34.8%</td>
<td>33.2%</td>
<td>51.0%</td>
<td>11.9%</td>
<td>9.4%</td>
<td>8.5%</td>
</tr>
<tr>
<td>2021</td>
<td>13.1%</td>
<td>40.0%</td>
<td>7.3%</td>
<td>54.5%</td>
<td>28.7%</td>
<td>28.1%</td>
<td>45.3%</td>
<td>10.5%</td>
<td>7.7%</td>
<td>6.4%</td>
</tr>
<tr>
<td>2022</td>
<td>13.2%</td>
<td>41.0%</td>
<td>7.2%</td>
<td>58.7%</td>
<td>27.7%</td>
<td>28.0%</td>
<td>47.0%</td>
<td>10.0%</td>
<td>7.0%</td>
<td>6.6%</td>
</tr>
</tbody>
</table>

Change, 2022 clearance rate vs.:

<table>
<thead>
<tr>
<th>Period</th>
<th>Total</th>
<th>Violent</th>
<th>Property</th>
<th>Homicide</th>
<th>Rape</th>
<th>Robbery</th>
<th>Assault</th>
<th>Burglary</th>
<th>Vehicle theft</th>
<th>Larceny/ theft</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990-94</td>
<td>-38%</td>
<td>-12%</td>
<td>-55%</td>
<td>+1%</td>
<td>-47%</td>
<td>+16%</td>
<td>-21%</td>
<td>-22%</td>
<td>-29%</td>
<td>-66%</td>
</tr>
<tr>
<td>2005-09</td>
<td>-26%</td>
<td>-4%</td>
<td>-47%</td>
<td>+6%</td>
<td>-35%</td>
<td>+7%</td>
<td>-11%</td>
<td>-22%</td>
<td>-10%</td>
<td>-59%</td>
</tr>
</tbody>
</table>

Source: DOJ (2022). Note: Rates for each 5-year period are the annual average for that period.
THE RISKS ARE AS REAL AS THE BENEFITS

Why African Americans say "No": A Study of Pharmacogenomic Research Participation

<table>
<thead>
<tr>
<th>Reasons patients gave for declining participation by category</th>
<th>Mean age in years [SD]</th>
<th>% Male</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study requires too much blood</td>
<td>67.06 [13.1]</td>
<td>43.8</td>
<td>16 (19.5)</td>
</tr>
<tr>
<td>Mistrust of research</td>
<td>66.2 [16.3]</td>
<td>60</td>
<td>10 (12.2)</td>
</tr>
<tr>
<td>Concerns about genetic testing</td>
<td>54.6 [16.9]*</td>
<td>83.3</td>
<td>12 (14.6)</td>
</tr>
</tbody>
</table>

Table 2.
Final coding categories and exemplar quotes

<table>
<thead>
<tr>
<th>Coding Category</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study requires too much blood</td>
<td>&quot;That’s a lot of blood. I have been poked too many times already since I’ve gotten here.”</td>
</tr>
<tr>
<td>Mistrust of research</td>
<td>&quot;I don’t want my information in a database.&quot;</td>
</tr>
<tr>
<td>Concerns about genetic testing</td>
<td>&quot;You know the police can get access to your genetic information.”</td>
</tr>
<tr>
<td>Too little time</td>
<td>&quot;I don’t have time. I’m trying to rush out of here.”</td>
</tr>
<tr>
<td>No direct health benefit to participant</td>
<td>&quot;How does this help me? There will be others more interested in participating.”</td>
</tr>
<tr>
<td>Is/has been in too many studies</td>
<td>&quot;I’m already enrolled in a study in North Carolina.”</td>
</tr>
<tr>
<td>Not enough compensation</td>
<td>&quot;If I’m giving my blood, I should get paid.”</td>
</tr>
<tr>
<td>No reason given</td>
<td>&quot;I’ve just decided not to [participate].”</td>
</tr>
<tr>
<td>Other</td>
<td>&quot;I have too much going on already as it is.”</td>
</tr>
</tbody>
</table>

Factors associated with participation by African Americans in a study of the genetics of glaucoma

Subjects who did not enroll in the POAAGG study were primarily distinguished by their discomfort in providing DNA for research studies. Many studies have cited mistrust in research as the most commonly identified barrier to study participation among African Americans (Kaufman et al. 2008; Russey-Jones et al. 2009; Rivers et al. 2013). In fact, surveys have shown that only 25% (Mouton et al. 1997) to 44% (Millon-Underwood, Sanders, and Davis 1993) of African Americans view research in the United States as ethical. This underlying attitude of mistrust likely contributes to subjects declining to participate in the study.
The risks are as real as the benefits

Despite mandates by the federal government to ensure inclusion of women and minorities in all federally funded research, African Americans continue to participate less frequently than Whites. Lower participation rates among African Americans have been reported across various study types (e.g., controlled clinical treatment trials, intervention trials, as well as studies on various disease conditions, including AIDS, Alzheimer’s disease, prostate cancer and other malignancies, stroke, and cardiovascular disease).

Several factors that affect the participation of African Americans are discussed and their sociocultural factors are identified.

New Jersey Keeps Newborn DNA for 23 Years. Parents Are Suing

New Jersey stores them for decades and may allow them to be used in carrier tests for hereditary diseases.

Woman Sues San Francisco Over Arrest Based on DNA From Her Rape Kit

The woman had provided her DNA to police after being sexually assaulted in 2016, her lawyer said. About five years later, officers used it to charge her with retail theft.

Hospitals Face Tricky Scenarios With Law Enforcement Requests for Patient DNA

Hospitals are facing difficult decisions when law enforcement requests patient DNA. It is fair to ask whether mistreatment of African Americans that has occurred more recently than the Tuskegee syphilis study is exacerbating mistrust today.
At issue is whether a district court acted properly in excluding evidence of a so-called warrior gene variant linked to a predisposition toward aggressive and violent behavior as it weighed murder charges against Anthony Blas Yepaz. The Supreme Court listened to oral arguments from opposing attorneys without yet issuing a decision.
Association between MT erectile dysfunction and...
Maryland Code, Criminal Procedure § 17-102

- Warrant to do FIGG, certify that satisfy criteria (serious crime type, putative perpetrator, STR/reasonable efforts exhausted)
- Expressly prohibit medical/psychological traits or predispositions
- Only DTCs that have explicit notice and express consent
- Licensed laboratory
- Informed written consent for 3rd party samples, documented by video or audio; option to get court order to covertly collect if putative perpetrator/3rd party and necessary and minimization of intrusiveness
- Restrictions on use/destruction of samples and data in cases that do not result in prosecution; retention rules for genealogists
- Criminal penalties and civil liability for noncompliance
- Defense access for exonerative purposes pre- and post-trial
- Licensing program and requirements for labs and genealogists
- Detailed public disclosure of use with review by panel of stakeholders

REAL OVERSIGHT, WITH INPUT FROM BROAD STAKEHOLDERS, IS IMPERATIVE

Ram, Murphy & Suter, Regulating Forensic Genetic Genealogy Science (2021)
In the absence of legislation, a federal interagency process must...

- Assess impacts and leverage federal power by tapping expertise **beyond DOJ/FBI stakeholders** including:
  - FTC (consumer protection, regulation of private providers, genetic and data privacy/retention, enforcement of Terms of Service & representations to consumers)
  - HHS/NIH (health and research privacy and equity, disability antidiscrimination, ethics, QA/QC standards from CLIA/Medicare context, data retention/reuse, etc.)
  - Interior (expertise in Tribal/Native American issues)
  - DHS (implications for national security, immigration equity)
  - DOD (implications for military/covert operations)
  - Treasury (implications for insurance, financial services, etc.)
  - Labor, Education (implications for student and worker privacy etc.)
  - Commerce (NIST expertise in forensics)
  - White House: OSTP, OMB, EOP/DPC, etc.

- Center and elevate the racial justice and racial equity concerns given (to quote President Biden’s EO) “the legacy of systemic racism in our criminal justice system and [the imperative to] work together to eliminate the racial disparities that endure to this day.”

- Take a data-driven, cost-benefit approach that require concrete data concerning efficacy, impact. Use RFP and other federal grant processes to develop and impose standards (licensing/oversight), tracking of key metrics, and transparent reporting of information.
Thank you!