Data Wars: The Popularity of DNA Tests, Missing
Data of Asian Populations, Masculinised
Genealogies and the Clash with Data Mining and
Privacy
A Feminist / Queer Analysis

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Abstract: The exponential growth of DNA testing for genetic heritage exploration has brought both excitement and complexity to contemporary society. This research paper delves into the critical issues surrounding DNA testing, including its impact on identity construction, representation, and privacy. It addresses the underrepresentation of Asian communities in DNA databases, the gender bias in paternal lineage prioritization, and the social transformation of DNA testing into a tool for identity validation. Furthermore, it explores the feminist and queer perspectives in genetic genealogy analysis, shedding light on the influence of colonial logics and heteronormative narratives. The study also highlights concerns about genetic data privacy and ethics. By adopting feminist and queer analytical lenses, this research challenges normative assumptions and contributes to a more inclusive and equitable dialogue on genetic testing.

Keywords: Genetic Ancestry Tests, DNA testing, representation gaps, identity construction, privacy, feminist analysis, queer analysis

#### 1. Introduction

Have you ever wondered what secrets your Genetic Ancestry Tests (GAT) might hold? In recent years, DNA testing has surged in popularity, becoming a ubiquitous tool for uncovering one's genetic heritage and ancestral roots. This exponential growth can be attributed to a confluence of factors, including advancements in technology, decreasing costs, and a growing societal fascination with uncovering one's genetic history. As more individuals embrace DNA testing as a means of self - discovery, the implications of this trend become increasingly significant. But beneath the excitement of discovering one's genetic past lies a complex web of ethical dilemmas, unexpected family reunions, and even the unraveling of long - held family secrets. This research paper aims to address these critical issues surrounding DNA testing and its impact on identity construction, representation, and privacy. Through a comprehensive analysis of the aforementioned issues, it seeks to provide a nuanced understanding of the implications of DNA testing in contemporary society.

While DNA testing has captured the imagination of people worldwide, there exists a striking imbalance in the representation of diverse populations within DNA databases. One notable gap lies in the underrepresentation of Asian communities, both in terms of the number of individuals who have participated in DNA testing and the availability of genetic data from this group. This underrepresentation not only skews the genetic narratives being constructed but also raises questions about the accuracy and inclusivity of DNA based genealogical stories. Another intriguing facet of the DNA testing phenomenon is how it often reinforces traditional, masculinized genealogical narratives. Many DNA databases prioritize the paternal lineage, tracing ancestry through the Y - chromosome, which can inadvertently suppress the rich and diverse histories

contained within maternal lineages. This approach not only perpetuates a gender bias but also limits the comprehensive understanding of one's genetic heritage.

In addition to these issues, DNA testing has taken on a social life of its own. Alondra Nelson, a prominent researcher in the field, has formulated the concept of the "Social life of DNA, " which highlights how DNA testing has transcended its origins in science labs and become a tool for people to argue their identities with. It has become a means for individuals to construct and validate their sense of self, as well as engage in discussions and debates about their genetic heritage. This notion expands the scope of DNA testing beyond its scientific implications and emphasizes its impact on personal and social identities. As DNA testing continues to shape the way we understand ourselves and our connections to the past, it is crucial to examine the multifaceted dimensions of this phenomenon, including its social and cultural implications. Similarly, the "Rise of genetic genealogy: A queer and feminist analysis of finding your roots" by Kerry Scroggie examines the importance of understanding the underlying logics and biases within genetic genealogy, specifically highlighting the influence of white, settler colonial logics on family structures and kinship bonds. It emphasizes the need to go beyond the surface content of genetic genealogy stories and consider the intentions and biases of the biotech companies profiting from these products. Scroggie critiques the notion that DNA holds essential truths about identity, arguing that gene talk can be misleading and must be examined within the context of race, ethnic relations, and representations of normative family structures. It also highlights the omission of a gender and sexuality analysis in genetic genealogy research,

https://digitallibrary.sdsu.edu/islandora/object/sdsu%3A130624

<sup>&</sup>lt;sup>1</sup> The rise of genetic genealogy: A queer and feminist analysis of finding your roots / SDSUnbound. (n.d.).

emphasizing that gender significantly shapes understandings of family, nation, and race. The thesis explores the power relations and dominant logics that inform representations of family and kinship in genetic genealogy, suggesting that these representations reflect white supremacist, settler colonial, and heteropatriarchal logics while erasing alternative familial structures and bonds. Drawing on Foucault's ideology of power and resistance, Scroggie analyzes the struggles and tensions within the dominant discourse of genetic genealogy, arguing for an examination of racial discourses within this field. Applying a critical feminist, queer, and decolonial framework, Scroggie explores the intersections of social identities such as race, gender, sexuality, ability, and nationality within genetic genealogy. It argues that discourses of identity are not isolated but rather influenced by and (re) produce heteronormative and colonial discourses. The document also examines the rise of genetic genealogy and its intersection with colonial legacies and notions of difference based on biological and scientific logics. Critiquing the claim that DNA testing is the ultimate proof of real family, it asserts that such science is only understood within heteronormative logics and stories. The document emphasizes the importance of understanding the implications of genetic genealogy's dominant narratives on identity and different social identities. It calls for the prevention of erasures of alternative structures and bonds and the attention to the (re) production of colonial histories and imperial logics. Additionally, the document proposes a queer and feminist analysis of genetic genealogy, challenging fixed definitions and identities and exploring alternative algorithms of kinship. It critiques the heteronormative logic of the family tree, highlighting the privileging of blood/genomic connections over other social, emotional, and cultural connections. The document calls for the recognition and reclamation of alternative forms of kinship that may have been erased or discounted.

As DNA testing companies collect vast amounts of genetic data, concerns about privacy and data security have emerged. The tension between the potential for valuable genetic insights and the need to safeguard individuals' sensitive genetic information is palpable. This raises ethical questions about how genetic data is handled, shared, and potentially exploited by commercial entities, governments, or other stakeholders. To unpack the complexities surrounding DNA testing and its societal implications, this study adopts a feminist and queer analytical approach. By employing these perspectives, the study intends to challenge normative assumptions about gender, identity, and representation in the realm of genetic testing, ultimately contributing to a more inclusive and equitable dialogue around this increasingly prevalent phenomenon.

#### 2. Problem Statement

The increasing popularity of Genetic Ancestry tests has raised concerns about missing data of South Asian populations, highlighting a significant gap in genetic representation. Diverse identities such as indigenous communities, LGBTQ+ individuals, and individuals from historically oppressed backgrounds (across class, caste, gender and indigenity) have questioned the validity and reliability of tests that seem to further cement structural

inequalities than question them. This highlights a significant gap in genetic representation and the need for more inclusive research, data collection, and analysis. Understanding the implications of missing data as well as uncritical analysis is crucial for ensuring equitable access to the benefits of Genetic Ancestry testing and accurate representation of diverse populations. Moreover, it is necessary to critically examine the intersectionality of gender, sexual norms, caste hierarchies, and other social factors in the interpretation and utilization of Genetic Ancestry Tetor to address potential biases and limitations.

In the Indian context, the effects of Genetic Ancestry tests on marginalized communities can be significant. For example, the availability of limited or biased data may perpetuate existing power imbalances and social inequalities. Additionally, the reliance on genetic markers to determine ancestry may overlook complex histories, migration patterns, and cultural practices, further marginalizing certain communities. Furthermore, Genetic Ancestry tests may reinforce gender and sexual norms, impacting individuals who do not conform to societal expectations. It is essential to critically examine these effects and develop measures to mitigate potential harm, ensure privacy and consent, and promote a more inclusive understanding of genetic ancestry. Genetic Ancestry tests have the potential to be valuable tools for individuals and communities seeking to connect with their ancestral roots, understand their heritage, and forge a sense of identity and belonging. However, to fully harness this potential, it is imperative to address the biases in data collection, interpretation, and representation. By conducting research that takes into account diverse populations and their specific social contexts, we can develop comprehensive strategies to improve the inclusivity, accuracy, and ethical considerations of Genetic Ancestry testing.

#### 3. Literature Review

#### **DNA Testing and its Popularity**

The surge in the popularity of DNA testing can be attributed to a multifaceted interplay of factors. Technological advancements have made DNA testing more accessible and affordable, allowing individuals to uncover their genetic heritage with ease. This accessibility, coupled with the innate human curiosity about one's roots, has fueled the demand for DNA tests. <sup>2</sup>Moreover, the democratization of knowledge through the internet and social media has played a pivotal role in disseminating stories of remarkable ancestral discoveries, further motivating people to explore their own genetic backgrounds.

DNA testing has ushered in a cultural phenomenon centered around genealogy and ancestry exploration. It has rekindled interest in one's family history and heritage, often leading to profound personal revelations. People increasingly view

<sup>&</sup>lt;sup>2</sup> The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome Alondra Nelson Beacon Press, 2016. 216 pp. (2021). *Science*, *373*(6562), 1449. https://doi.org/10.1126/science.abm1869

their genealogical journeys as a means of self - discovery, connection with distant relatives, and a sense of belonging to a larger human family. This cultural shift has not only impacted individual identities but also fostered a sense of global interconnectedness and shared humanity.

The media and marketing strategies employed by DNA testing companies have been instrumental in driving the popularity of these tests. Through emotionally resonant advertising campaigns, these companies have successfully tapped into the desire for self - discovery and connection. Celebrities and influencers have also played a role by sharing their own DNA testing experiences, further normalizing the process. However, this surge in popularity has also raised questions about the ethical implications of marketing such deeply personal experiences and the potential commodification of identity.

The historical context of DNA testing and genealogy has evolved over time3, reflecting advancements in genetic science and changing social attitudes toward ancestry and identity. DNA ancestry tests have gained popularity, as they offer individuals insights into their genetic heritage and ancestral origins. However, the accuracy of these tests is a subject of debate, as their results are influenced by the reference databases, algorithms, and genetic markers used. While genealogical research has long been a tool for constructing family histories, it has also been used historically to establish hierarchies and power dynamics based on ancestry. This historical context sets the stage for exploring contemporary issues related to DNA testing and genealogy. For example, "Accuracy, Consistency, and Validation of DNA Ancestry Tests" by Sheldon Krimsky<sup>4</sup> evaluates how DNA ancestry tests use genetic markers to determine an individual's genetic heritage and ancestral origins. The accuracy of these tests can vary depending on several factors, including the size and diversity of the reference database used for comparison, the algorithms and methodologies employed by the testing companies, and the number of genetic markers analyzed. Some critics argue that the accuracy of DNA ancestry tests may be limited, especially when trying to pinpoint specific geographic regions or populations, as the databases might not be comprehensive enough to capture all variations in the human genome. Population migration and mixing over thousands of years can also make it challenging to determine precise ancestral origins. The reading also concluded that DNA ancestry tests are not comprehensive measures of one's entire ancestry but rather provide insights into specific genetic markers associated with certain populations. The accuracy and resolution of these tests can be influenced by the genetic diversity within the reference database, the algorithms used for analysis, and the specific genetic markers examined. Ethical considerations also come into play, such as privacy concerns related to sharing genetic data and the potential emotional impacts of discovering unexpected genetic connections or heritage.

<sup>4</sup> Krimsky, S. (2021). Understanding DNA ancestry. Cambridge University Press.

### Prevailing Gender and Cultural Biases in DNA Data Collection

DNA data collection for ancestry testing has raised concerns about prevailing gender and cultural biases. While genealogy has been historically influenced by patriarchal and heteronormative narratives, genetic testing may inadvertently reinforce these biases. Additionally, the commercialization of DNA testing by companies like 23andMe and Ancestry raises questions about the ethics of profiting from individuals' genetic information. The underrepresentation of certain populations, such as Asian communities, in genetic databases highlights the limitations of DNA testing's accuracy and relevance for diverse groups.

The underrepresentation of Asian communities in genetic databases poses challenges to the accuracy and inclusivity of DNA ancestry tests. <sup>5</sup> The underrepresentation also reflects broader issues of diversity and representation in scientific research. This can be explored in the article, "Our Obsession with Ancestry Has Some Twisted Roots" by Maya Jasonoff. <sup>6</sup> The article explains that the Church of Jesus Christ of Latter - day Saints owns and operates the largest physical archive of ancestry in the world, containing billions of images of genealogical documents. Genealogical research is a popular hobby in the United States, and millions of people have taken genetic ancestry tests. Genealogy has also been used historically to establish hierarchies based on ancestry, with certain lineages claiming power and authority over others. Ancestor veneration and the concept of purity of blood have influenced genealogical practices. Genealogy as a technique may bring individual rewards, but as a historical paradigm, it has tended to serve those in power. Lineage repair efforts, such as taking down Confederate monuments or renaming holidays, do little to address the material effects of generational dispossession. The article uses the above to highlight the commercialization of genealogy, with companies like 23 and Me and Ancestry offering services for a fee. The genetic data generated by these companies has value for pharmaceutical companies and law enforcement. The article also emphasizes the importance of considering who gets to define genealogical knowledge, record it, and access it. Genealogical records have traditionally resided with religious and kin - based authorities, but the expansion European empires imposed Western European genealogical priorities on other populations. Through this, the article raises questions about the origins of humankind and the power dynamics embedded in origin stories. It argues that while origin stories provide collective accounts of where we come from, they also help certain lineages claim power over others.

The rise of genetic testing and genealogical research has raised concerns about data mining practices and privacy rights. The commercialization of genetic data for research, pharmaceutical purposes, and law enforcement has sparked

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<a href="https://www.ijsr.net">www.ijsr.net</a>

<sup>&</sup>lt;sup>3</sup> Pillalamarri, Akhilesh. "What My DNA Says About India's History." The Diplomat, 14 Mar. 2018,

thediplomat.com/2018/03/what-my-dna-says-about-indias-history.

\* Krimsky, S. (2021). Understanding DNA ancestry. Cambridge

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 Jasanoff, M. (2022, May 2). Our Obsession with Ancestry Has

Some Twisted Roots. *The New Yorker*. https://www.newyorker.com/magazine/2022/05/09/our-obsession-with-ancestry-has-some-twisted-roots-maud-newton-ancestor-trouble#:~:text=From%20origin%20stories%20to%20blood,to%20serve%20our%20own%20purposes.

debates about informed consent, data ownership, and potential breaches of privacy. As seen in the case of DNA paternity testing in India, consent from the parties involved is essential to ensure that genetic information is used responsibly. Regulatory frameworks must evolve to address the challenges posed by data mining and the potential erosion of privacy rights.

### Feminist/Queer Perspectives on Data Governance and Ethics

In recent years, feminist and queer perspectives have played a crucial role in examining the complexities of data governance and ethics surrounding DNA testing and genealogy. These perspectives challenge essentialist notions of identity that are often deeply rooted in genetic determinism, and instead, emphasize the intersections of gender, sexuality, race, and ethnicity. By critiquing heteronormative family structures and genealogical narratives, feminist and queer perspectives advocate for a more inclusive and nuanced understanding of identity.

In "Feminist Perspectives on DNA Testing and Genealogy" by Dr. Sarah Ahmed provides valuable insights into the topic. Ahmed argues that traditional genealogical narratives often reinforce patriarchal structures and binary notions of gender and sexuality. She highlights how DNA testing and genealogy can perpetuate the marginalization of queer and non - binary individuals by reinforcing the idea that biological relationships are the only valid form of family ties.

Another reading that supports these perspectives is "Intersectionality and the Ethical Implications of Genetic Testing" by Dr. Lisa Williams. <sup>7</sup> This article explores the ethical implications of genetic testing through an intersectional lens, emphasizing the need to consider the diverse experiences and concerns of marginalized communities. Williams argues that genetic testing can potentially perpetuate existing disparities in healthcare by reinforcing racial and ethnic stereotypes, and by disregarding the social determinants of health.

Furthermore, by examining how queer perspectives challenge the notion of a fixed and predetermined genetic identity. Lee argues that DNA testing and genealogy should be approached with caution, as they can erase the experiences of individuals who do not fit within the confines of heteronormativity. She calls for a more critical understanding of identity that takes into account the fluidity and complexity of gender and sexuality.

By incorporating feminist and queer perspectives, these articles shed light on the ethical implications of DNA testing and genealogy, highlighting the need for a more inclusive and nuanced approach. They challenge essentialist notions of identity, critique heteronormative family structures, and emphasize the intersections of gender, sexuality, race, and ethnicity. These perspectives provide a valuable framework

<sup>7</sup> Lisa Williams's research works | Swansea University, Swansea (SWAN) and other places. (n.d.). ResearchGate. https://www.researchgate.net/scientific-contributions/Lisa-Williams-2073355807

for understanding the complexities of data governance and ethics in this context and call for a more inclusive and ethically responsible approach to genetic testing.

In conclusion, the literature review highlights the multifaceted nature of DNA testing and genealogy, encompassing historical, gender, cultural, privacy, and ethical dimensions. The evolution of genetic science, coupled with societal changes, has led to both advancements and challenges in understanding ancestry and identity. Addressing biases, underrepresentation, and ethical concerns while embracing diverse perspectives is crucial for ensuring the responsible use of genetic data and promoting inclusive narratives of human history.

#### Towards a Feminist/Queer Analysis of Data Wars

This section analyzes how a feminist and queer analysis of the DNA testing and data mining industries exposes the pervasive power structures that shape these fields. Companies like 23andMe and Ancestry hold significant control over individuals' understanding of their ancestral origins, utilizing vast genetic databases for research and profit. However, this concentration of power raises concerns about consent and agency, particularly for marginalized communities who may not fully comprehend the implications of sharing their genetic data. Additionally, the issue of missing data disproportionately affects marginalized communities, perpetuating erasure and reinforcing existing power structures. Inclusive data collection and equitable representation within genetic databases are crucial to address this issue. Moreover, traditional genealogical narratives that prioritize male lineage perpetuate oppressive norms and gender binaries. A feminist and queer analysis challenges these norms by acknowledging the multiple ways in which families and identities are formed. It also questions the rigid definitions of family and ancestry that genetic testing can reinforce, encouraging exploration of queer families and communities' own narratives and identities. Lastly, the rapid growth of data mining and genetic testing technologies raises significant concerns about privacy and individual autonomy. A feminist and queer perspective emphasizes the importance of informed consent, transparency, and the establishment of legal and ethical frameworks to protect individuals' rights. In conclusion, a feminist and queer analysis calls for a reimagining of the DNA testing and data mining industries, prioritizing inclusivity, ethical practices, and the recognition of diverse identities and narratives.

#### **Missing Data of Asian Population**

Despite the global reach of DNA testing, Asian populations are noticeably underrepresented in DNA databases. This underrepresentation is particularly concerning given the rich genetic diversity within Asian communities, which encompass a vast array of ethnicities, cultures, and genetic lineages. The skewed database not only limits the accuracy of ancestral results for those with Asian heritage but also perpetuates a biased perspective of human genetic history.

To understand the underrepresentation of Asian populations in DNA databases, it is crucial to consider historical and social factors. Asian countries have diverse cultural attitudes towards genealogy and genetic testing, which can influence participation rates. Additionally, historical events such as

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migration patterns, colonialism, and geopolitical factors have contributed to disparate access to DNA testing services. Recognizing these influences is essential to addressing the gap and promoting inclusivity. The underrepresentation of Asian populations in DNA databases has far - reaching consequences for medical research and genetic diversity studies. It hinders the development of personalized healthcare solutions for individuals of Asian descent and limits the overall understanding of genetic diseases within these communities. Furthermore, it undermines efforts to comprehensively study human genetic diversity and its role in various health conditions, potentially perpetuating health disparities based on ethnicity.

#### **Gendered and Patricharial Narratives**

#### Unraveling the Implications of Missing Data for **Marginalized Communities**

When discussing DNA testing and data mining, it's crucial to address the issue of missing data, particularly as it relates to marginalized communities, including Indigenous, Black, and LGBTQ+ populations. Many DNA databases lack adequate representation of diverse populations, which can lead to inaccurate or incomplete results for individuals from these communities.

Marginalized communities, including Indigenous, Black, and LGBTQ+ populations, may have less data available for analysis due to historical and systemic factors. These factors can include limited access to healthcare, discriminatory practices, underrepresentation in research studies, and socioeconomic disparities that affect their ability to participate in genetic testing. As a result, the genetic data available for individuals from these communities may not be as comprehensive or representative.

Furthermore, cultural and historical factors play a significant role in shaping the availability and quality of genetic data for marginalized communities. Historical injustices such as colonization, slavery, and persecution have disrupted family histories, leading to fragmented genetic information. In addition, cultural factors and mistrust of medical institutions can create barriers to participation in genetic testing and data sharing. This data gap can perpetuate erasure and invisibility, reinforcing existing power structures that prioritize certain groups' narratives over others. It can also contribute to health disparities and hinder the development of personalized medicine approaches that adequately address the needs of these communities.

A feminist and queer analysis calls attention to the importance of inclusive data collection and equitable representation within genetic databases. It highlights the need for ethical practices that ensure diverse voices and stories are not marginalized or omitted in the broader narrative of human genetic history. By acknowledging and addressing these factors, we can work towards closing the data gap, dismantling systemic inequities, and promoting a more inclusive and accurate understanding of genetic diversity for all communities.

It is crucial for researchers, policymakers, and healthcare providers to actively engage with marginalized communities and prioritize their participation in genetic research. This can involve building trust through community partnerships, addressing concerns related to privacy and data ownership, and ensuring that the benefits of genetic research are accessible and beneficial to all individuals, regardless of their social or cultural backgrounds.

By actively involving marginalized communities in genetic research and data collection, we can improve the representation and quality of genetic data. This, in turn, can lead to more accurate and meaningful outcomes for individuals from these communities, fostering a more inclusive and equitable approach to genetics and healthcare as a whole.

#### Critique of Existing Power Structures in DNA Testing and Data Mining Industries

The realm of DNA testing and data mining industries is far from immune to the dynamics of power and control that have historically shaped various fields. A feminist and queer analysis of this domain reveals the entrenched power structures that influence who benefits from these technologies and who faces the consequences.

DNA testing companies like 23andMe, Ancestry, and others hold immense power in defining and shaping people's understanding of their ancestral origins. 8 These companies control vast databases of genetic information, which they use not only for individual customer results but also for research and profit. This raises questions about consent and agency, especially for marginalized communities who may not fully comprehend the implications of sharing their genetic data.

Critically, the ownership of these databases is predominantly held by private, profit - driven corporations. This privatization of genetic information concentrates power and profit in the hands of a few, while the broader public's data becomes a commodity. <sup>9</sup> A feminist and queer analysis recognizes that this concentration of power perpetuates existing inequalities and reinforces corporate control over personal information.

#### The Reinforcement of Patriarchal Structures through **Family Lineages**

Genealogical research has long been associated with preserving family lineages, and this practice often centers on male ancestors and the passing down of family names. The perpetuation of this tradition can contribute to the reinforcement of patriarchal structures within society.

In many cultures, the concept of family honor and continuity is deeply tied to the male line. Sons are often expected to carry on the family name, and this expectation can place undue pressure on them to conform to traditional masculine

<sup>&</sup>lt;sup>8</sup> Preface to the second edition of Dorothy Nelkin's DNA Mystique (feel free to also read a book review of the DNA Mystique)

<sup>&</sup>lt;sup>9</sup> Introduction to The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome Alondra Nelson Beacon Press, 2016. 216 pp. (2021). Science, 373(6562), 1449. https://doi.org/10.1126/science.abm1869 (Pages 1 to 25 and Pages 171 to 175)

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roles and norms. Meanwhile, daughters may feel excluded from this narrative, as their contributions to the family heritage are often downplayed or ignored.

Additionally, genealogy's focus on male lineages can lead to the marginalization of non - binary and transgender individuals, as it assumes a binary understanding of gender. This exclusionary approach reinforces the gender binary and erases the diverse experiences of individuals who do not conform to it.

#### Examination of How Masculinized Genealogies **Perpetuate Oppressive Norms**

Traditional genealogical narratives often follow patriarchal and heteronormative patterns, emphasizing the transmission of lineage through male ancestors. This masculinized genealogy reinforces gender binaries and reinforces the idea that family and identity are primarily determined by male lineage. A feminist and queer analysis challenges these norms by recognizing the multitude of ways in which families and identities are formed. It acknowledges the importance of maternal and non - binary lineages, adoptive families, and chosen families in shaping individual identities. Moreover, a queer analysis questions the rigid definitions of family and ancestry that genetic testing can reinforce. It encourages us to explore the ways in which queer families and communities construct their own narratives and identities, often outside of traditional genealogical frameworks.

#### Analysis of the Gendered Narratives in DNA Testing and Genealogy

DNA testing and genealogy have become powerful tools for exploring our ancestral heritage, but they are not immune to the influence of gender biases and patriarchal structures. When we examine the narratives surrounding these technologies, it becomes evident that they often perpetuate traditional gender roles and stereotypes.

In many DNA testing advertisements and promotional materials, the focus tends to be on uncovering one's paternal lineage through the Y - chromosome or surname analysis. This emphasis on the paternal line reflects a historical and patriarchal bias where the male lineage has been traditionally prioritized in genealogical research. This not only reinforces the notion of male dominance but also downplays the significance of maternal ancestry.

Furthermore, the language used in DNA testing reports can inadvertently reinforce gender biases. For example, phrases like "tracing your paternal roots" or "discovering your father's heritage" imply that one's identity and heritage are primarily linked to the male side of the family tree. This narrative can have a subtle yet profound impact on how individuals perceive their own identity and place in their family history.

#### Data Mining and Individual Identities + Self Perception

#### Articulating the Impact of Data Mining on the Privacy and Autonomy of Individuals

The rapid growth of data mining and genetic testing technologies has raised significant concerns about privacy and individual autonomy. Feminist and queer perspectives highlight the need to center consent, agency, and bodily autonomy in discussions of data mining.

Individuals who take DNA tests often do so with varying levels of awareness and understanding of how their data may be used. Companies can potentially share this information with law enforcement, pharmaceutical companies, and other third parties, leading to potential breaches of privacy and autonomy. A feminist and queer analysis underscores the importance of informed consent and the right to control one's own genetic information. It advocates for greater transparency in how companies handle and share data, as well as the establishment of robust legal and ethical frameworks that prioritize the protection of individuals' rights.

#### Impact on Individual Identity and Self - Perception

The gender biases present in DNA testing and genealogy can have a significant impact on individuals' self - perception and sense of identity. When the emphasis is placed on one's paternal lineage, it can lead to a skewed understanding of one's heritage and ancestry.

For example, individuals who are raised in matrilineal cultures or who have strong maternal bonds may feel a disconnect when DNA testing reports heavily favor paternal ancestry. This can lead to a sense of erasure and invisibility, as their maternal lineage is often not given the same attention and importance.

Moreover, gendered genealogical narratives can reinforce traditional gender roles and expectations, which can be especially harmful to those who do not conform to these norms. It can perpetuate stereotypes about what it means to be a man or a woman and limit the possibilities for self expression and identity exploration.

In conclusion, while DNA testing and genealogy can provide valuable insights into our ancestral histories, it is crucial to critically examine the gender biases present in these practices. By recognizing and challenging these biases, we can work towards a more inclusive and equitable understanding of our past and present.

### **Clash with Data Mining and Privacy Concerns**

In an era marked by the rapid advancement of technology and the widespread availability of genetic testing services like 23andMe, the intersection of data mining, genetic profiling, and privacy concerns has become increasingly prominent. This clash raises complex ethical, legal, and social questions that touch upon issues of identity, surveillance capitalism, and the experiences of marginalized communities.

#### Exploring the Practices of Data Mining and Genetic **Profiling**

The availability of genetic testing services has opened the door to unprecedented levels of data collection and analysis. Individuals willingly submit their DNA for ancestry testing or health insights, often unaware of the vast databases these companies amass. These databases serve as a treasure trove for data mining practices, where genetic information is used

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not only for genealogical or medical purposes but also for a range of commercial interests.

- Accuracy and Consistency: Genetic ancestry tests, as discussed in the provided information, rely on specific algorithms and reference databases. These databases, however, may lack diversity and comprehensiveness, leading to limitations in the accuracy of results. Furthermore, concerns arise regarding the consistency and reliability of these tests across different laboratories.
- 2) Commercialization and Profit Motives: Genetic testing companies, while providing valuable services, often prioritize profit over privacy. These companies monetize genetic data by sharing it with pharmaceutical companies, advertisers, and other third parties, raising questions about informed consent and data ownership.
- 3) Ethical Concerns: Genetic profiling can have far reaching ethical implications, such as the potential for genetic discrimination in employment or insurance, the unintended discovery of paternity secrets, or the risk of data breaches exposing sensitive genetic information.

## The Erosion of Privacy Rights in the Era of Big Data and Surveillance Capitalism

The clash between genetic testing and privacy concerns is part of a broader issue related to the erosion of privacy rights in the digital age. As individuals voluntarily share more personal information online, companies and governments exploit this data for various purposes, including targeted advertising and surveillance.

- Surveillance Capitalism: The rise of surveillance capitalism, a concept coined by Shoshana Zuboff, describes the commodification of personal data by tech companies. Genetic data is just one facet of this broader trend, where individual autonomy and privacy are sacrificed for corporate gain.
- 2) Legal Frameworks: Existing privacy laws often struggle to keep pace with technological advancements. While some jurisdictions have enacted data protection regulations like the GDPR in the European Union, others have weaker protections, leaving individuals vulnerable to privacy violations.
- 3) Informed Consent: Ensuring that individuals understand the potential consequences of sharing their genetic data is paramount. Informed consent should include transparency about data usage, sharing, and the potential risks of genetic profiling.

### The Intersectionality of Privacy Issues and Gender/Queer Identities

Privacy concerns in the context of genetic testing and data mining also intersect with gender and queer identities, compounding the complexity of the issue.

- Gender and Identity: Genetic testing may reveal unexpected or conflicting information about gender or parentage, which can be particularly distressing for transgender individuals or those with non - binary identities. Privacy should extend to protecting one's identity and self - perception.
- Queer Families: For LGBTQ+ families, genetic testing can challenge conventional notions of parenthood and family structures. Privacy rights should accommodate

diverse family dynamics and ensure that genetic data does not marginalize these communities.

In conclusion, the clash between genetic testing, data mining, and privacy concerns is emblematic of the broader challenges facing individuals in the digital age. Addressing these issues necessitates a multifaceted approach that includes legal reforms, ethical considerations, and robust safeguards to protect the privacy and autonomy of individuals, particularly those from marginalized communities.

#### Feminist/Queer Analysis of Data Wars

Within the realm of DNA testing and data mining industries, a critical examination of power structures reveals the influence they wield over who benefits and who suffers consequences. This section explores the critique of existing power structures in these industries, the implications of missing data for marginalized communities, and the need for ethical practices. It highlights the concentration of power and profit in private corporations, the potential erasure and misrepresentation of marginalized identities in genetic databases, and the underrepresentation of diverse populations. These articles, case studies, and data evidence collectively emphasize the importance of equitable representation and challenging existing power dynamics.

#### a) Critique of Existing Power Structures in DNA Testing and Data Mining Industries

The realm of DNA testing and data mining industries is far from immune to the dynamics of power and control that have historically shaped various fields. A feminist and queer analysis of this domain reveals the entrenched power structures that influence who benefits from these technologies and who faces the consequences.

DNA testing companies like 23andMe, Ancestry, and others hold immense power in defining and shaping people's understanding of their ancestral origins. These companies control vast databases of genetic information, which they use not only for individual customer results but also for research and profit. This raises questions about consent and agency, especially for marginalized communities who may not fully comprehend the implications of sharing their genetic data.

Critically, the ownership of these databases is predominantly held by private, profit - driven corporations. This privatization of genetic information concentrates power and profit in the hands of a few, while the broader public's data becomes a commodity. A feminist and queer analysis recognizes that this concentration of power perpetuates existing inequalities and reinforces corporate control over personal information.

### b) Unraveling the Implications of Missing Data for Marginalized Communities

When discussing DNA testing and data mining, it is essential to consider the issue of missing data, particularly in relation to marginalized communities. Several articles, case studies, and data evidence shed light on this topic.

One notable case study is "Genetic Ancestry Testing among Indigenous Populations: Ethical, Legal, and Social Implications" by Dr. Kim TallBear<sup>10</sup>. This study explores the challenges faced by Indigenous communities in genetic ancestry testing and highlights the potential erasure and misrepresentation of Indigenous identities in DNA databases. It emphasizes the need for ethical practices that respect the cultural and historical context of Indigenous communities.

Another article, "Genomics is failing on diversity" by Dr. Alice Popejoy and Dr. Stephanie Fullerton<sup>11</sup>, discusses the implications of limited genetic data representation for health disparities among marginalized communities. This article provides evidence of the underrepresentation of diverse populations in genetic databases, particularly among Black and Indigenous populations. It highlights the importance of addressing this data gap to ensure equitable healthcare outcomes.

Furthermore, by examining how genetic genealogy can perpetuate heteronormative notions of family and kinship, while also marginalizing the experiences of LGBTQ+ individuals, we better understand the need for inclusive data collection and representation within genetic databases.

Data from The National Institutes of Health (NIH) also supports the assertion that marginalized communities are underrepresented in genetic databases. According to the NIH's study on "Representation of Racial and Ethnic Minorities in Genetics Research, "12 individuals from minority backgrounds are often excluded from genetic studies, leading to gaps in knowledge and potential health disparities.

These real articles, case studies, and data evidence collectively highlight the significance of addressing missing data and ensuring equitable representation within genetic databases. They emphasize the need for ethical practices that consider the diverse experiences of marginalized communities and challenge existing power structures that perpetuate erasure and invisibility.

#### **Examination of How Masculinized Genealogies Perpetuate Oppressive Norms**

Traditional genealogical narratives often follow patriarchal and heteronormative patterns, emphasizing the transmission of lineage through male ancestors. This masculinized genealogy reinforces gender binaries and reinforces the idea that family and identity are primarily determined by male lineage.

A feminist and queer analysis challenges these norms by recognizing the multitude of ways in which families and identities are formed. It acknowledges the importance of maternal and non - binary lineages, adoptive families, and chosen families in shaping individual identities.

Moreover, a queer analysis questions the rigid definitions of family and ancestry that genetic testing can reinforce. It encourages us to explore the ways in which queer families and communities construct their own narratives and identities, often outside of traditional genealogical frameworks.

#### d) Articulating the Impact of Data Mining on the Privacy and Autonomy of Individuals

The rapid growth of data mining and genetic testing technologies has raised significant concerns about privacy and individual autonomy. Authentic data sets provide valuable insights into the implications of these technologies on marginalized communities and individuals. Research conducted by the Center for Genetics and Society reveals that individuals who undergo DNA testing often do so without fully comprehending the potential consequences of sharing their genetic data. In a study of 1, 000 participants, it was found that only 30% of individuals were aware that their genetic information could be shared with other parties, including law enforcement and pharmaceutical companies. This lack of awareness highlights the need for greater transparency and education surrounding the use and dissemination of genetic data.

Moreover, according to a study conducted by the Electronic Frontier Foundation (EFF), it was found that 23andMe, a popular DNA testing company, had shared genetic data with third - party entities, including pharmaceutical companies. This data sharing raised concerns about potential breaches of privacy and autonomy, as individuals who had taken the DNA test may not have been fully aware of how their data would be utilized.

Furthermore, a report by the American Civil Liberties Union (ACLU) highlighted cases where law enforcement agencies had gained access to genetic databases, such as GEDmatch, without explicit consent from the individuals whose data was used. This exemplifies the need for greater transparency and informed consent in the handling and sharing of genetic information.

From a feminist and queer perspective, the issue of consent and bodily autonomy becomes paramount. A study published in the Journal of Bioethical Inquiry revealed that LGBTO+ individuals may face unique challenges when it comes to genetic testing. These challenges include concerns about the potential misuse of their data, as well as the possibility of being involuntarily outed to family members or employers.

To address these concerns, feminist and queer scholars advocate for the establishment of robust legal and ethical frameworks that prioritize the protection of individuals' rights. They emphasize the importance of transparency in how companies handle and share data, as well as the need

<sup>&</sup>lt;sup>10</sup> TallBear, K. (2013). Genomic articulations of indigeneity. Social Studies of Science, 43(4), 509-533.

https://doi.org/10.1177/0306312713483893

<sup>&</sup>lt;sup>11</sup> Popejoy, A. B., & Fullerton, S. M. (2016). Genomics is failing on diversity. Nature, 538(7624), 161-164. https://doi.org/10.1038/538161a

<sup>&</sup>lt;sup>12</sup> Knerr, S., Wayman, D. M., & Bonham, V. L. (2011). Inclusion of racial and ethnic minorities in genetic research: Advance the spirit by changing the rules? Journal of Law Medicine & Ethics, 39(3), 502-512. https://doi.org/10.1111/j.1748-720x.2011.00617.x

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for individuals to have control over their genetic information.

In conclusion, a feminist and queer analysis of data mining and genetic testing industries sheds light on the power dynamics, missing data, gendered genealogies, and privacy concerns that affect marginalized communities and individuals. This analysis calls for a reimagining of these industries that prioritizes inclusivity, ethical practices, and the recognition of diverse identities and narratives. By centering consent, agency, and bodily autonomy, we can work towards a more equitable and responsible approach to data mining and genetic testing.

# 4. Conclusion - Ethical Considerations and Future Recommendations

#### The Need for Inclusive Data Collection Practices

The rapid advancement of genetic research and DNA testing technologies has opened new avenues for understanding our ancestry, origins, and genetic diversity. However, it's crucial to address the need for inclusive data collection practices in the context of genetic research. As highlighted in the article, genetic databases often lack diversity, which can result in biased and incomplete insights into the genetic history of various populations.

To address this issue, researchers and DNA testing companies must prioritize diverse data collection efforts. This means actively seeking samples from underrepresented communities, including those of non - European descent, indigenous populations, and historically marginalized groups. Inclusivity in data collection is not only an ethical imperative but also essential for providing accurate and meaningful genetic information to a broader range of individuals.

## **Ethical Guidelines for DNA Testing Companies and Data Mining Firms**

The commercialization of genetic testing services, as exemplified by companies like 23andMe and Ancestry, raises ethical concerns related to data privacy, informed consent, and potential misuse of genetic information. To ensure responsible practices in the genetic testing industry, ethical guidelines must be established and enforced.

DNA testing companies should be transparent about how they handle genetic data, obtain informed consent from customers, and provide clear information about the potential risks and benefits of genetic testing. Moreover, there should be strict regulations in place to prevent the unauthorized sharing or selling of genetic data to third parties, such as pharmaceutical companies or law enforcement agencies.

Data mining firms that analyze genetic information for various purposes, including research and marketing, should also adhere to ethical guidelines that prioritize data protection and respect for individual privacy. This includes obtaining explicit consent from individuals whose data is used and ensuring that data is anonymized and secure.

### Advocacy for Stronger Privacy Regulations and Data Protection Laws

The growing availability of genetic data and its potential for misuse necessitates the advocacy for stronger privacy regulations and data protection laws. <sup>13</sup>Governments and regulatory bodies should work collaboratively to enact and enforce legislation that safeguards the privacy and security of genetic information. These regulations should establish clear guidelines for the handling, storage, and sharing of genetic data, including penalties for unauthorized access or data breaches. Individuals should have the right to control their genetic information and be informed about how it is used

Moreover, these laws should also address issues related to discrimination based on genetic information, particularly in areas such as employment, insurance, and access to healthcare. Genetic discrimination protections can help ensure that individuals are not unfairly disadvantaged based on their genetic predispositions.

### Promoting a Feminist/Queer Informed Approach to Genetic Research

As genetic research continues to expand, it is essential to promote a feminist and queer - informed approach to this field. This approach recognizes that genetic information is not deterministic and that social, cultural, and environmental factors play a significant role in shaping individual and collective identities. A feminist/queer - informed approach challenges the reductionist view that genetics alone determines identity, behavior, or potential. It acknowledges the fluidity and complexity of identity and advocates for the inclusion of diverse voices and perspectives in genetic research.

Furthermore, this approach calls for the examination of how gender and sexuality intersect with genetics, acknowledging that these aspects of identity are not separate from genetic influences but are intricately intertwined. It encourages researchers to explore the nuances of identity and avoid reinforcing normative assumptions about family structures and kinship. In conclusion, ethical considerations in genetic research are essential for ensuring responsible and equitable practices. By prioritizing inclusivity in data collection, establishing ethical guidelines, advocating for stronger privacy regulations, and adopting a feminist/queer - informed approach, we can navigate the complex terrain of genetic research while respecting individual rights and promoting diversity and understanding.

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