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Family History and the Global Politics of DNA

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Abstract:

The global DNA ancestry industry appeals to various “markets”: diasporic groups seeking to reconstruct lost kinship links; adoptees looking for biological relatives; genealogists tracing their family trees; and those who are merely curious about what DNA can reveal about their identity. However, the language of empowerment and openness employed by DNA ancestry-testing companies in their publicity materials masks the important commercial and private interests at stake. Drawing particularly on the experiences of Native and Indigenous American communities, this article highlights some of the contradictions and dilemmas engendered by the industry, and questions to what extent its practices can empower users without infringing upon the rights of other groups.

Keywords: DNA ancestry testing, ethics, Indigenous rights, identity

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People take DNA ancestry tests for multiple reasons. Some of the earliest advocates of the DNA ancestry-testing market were Jewish and African American scientists, who portrayed these technologies as a source of empowerment, healing, and a means to recover kinship links effaced by genocide and forced migrations.¹ DNA testing is also seen as a way of levelling the playing field for groups attempting to trace their biological ancestry without recourse to documentary sources, such as adoptees, or *stolen children*.² The majority of customers, however, do not fall into these groups but rather see DNA tests as tools for genealogical research or as a means of confirming or challenging their assumptions about their ethnic background. While DNA ancestry-testing is regarded by some as a potentially life-changing act, for others it is simply a bit of fun.³

Overall, these disparate users are united by the idea that their DNA can tell them something meaningful about who they are, and where they come from. This meaning is produced by *connections*: businesses link their customers to abstract *ethnic* clusters and *ancestral* regions, and set up matches among users based on their shared genomic inheritance. The underlying assumption is that everyone has the right to discover their family and origins, and so the more knowledge we share about the past, the better. Customers are therefore encouraged to opt in to *relative matching* features, upload their family tree, and fill in questionnaires about their health and physical traits to improve the power and accuracy of the company’s DNA estimates and the quality of information they, and others, stand to gain from these services.

This spirit of altruism masks the fact that DNA ancestry companies have a vested commercial interest in collecting huge amounts of genomic information from people around the world. In the last quarter of 2017 alone, AncestryDNA – currently the largest DNA ancestry test provider in the world – posted over US\$1 billion in revenue.⁴ This was also the first year that the total number of DNA kits sold by the enterprise exceeded the total number of subscribers to its family history services.⁵ Other companies, like 23andMe, have shaped their financial model around monetizing large, anonymized genetic datasets – along with metadata collected from participating customers – to pharmaceutical businesses.⁶ To date, some 30 million testing kits have been processed by direct-to-consumer (DTC) genetic ancestry companies worldwide.⁷

The past year has also seen new revelations regarding the ways these companies’ databases – as well as those of third-party sites like GEDmatch – have been utilized by law-enforcement agencies, for example to inform police investigative work and irregular migration cases.⁸ Political uses of genetic ancestry continue to grab headlines, as in the case of US Senator Elizabeth Warren’s widely criticized attempt to dismiss rumors about her Native American ancestry by having her DNA analyzed,⁹ and her subsequent announcement of support for historical reparations for Native Americans and African Americans – a project that may raise future debates about the utility of DNA (or other ways of assessing ancestry) for discerning the *legitimate* beneficiaries of such policies.¹⁰ While the scope and popularity of DNA ancestry-testing businesses continues to grow worldwide, these cases have highlighted the need for continued critical scrutiny of the ethical, social, and economic dimensions of this industry. From our combined personal and professional experience as an Indigenous geneticist-ethicist who works with US tribal communities and a social scientist who has studied the evolution of this phenomenon for several years, we suggest three questions that can provide a focus for future discussion and action.

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1 Identity: Right or resource?

The DNA ancestry-testing industry is made economically viable by customers who are disproportionately wealthy, Euro-descendant, and from the Global North. While it has undoubtedly brought benefits to many clients, the market's success has also been propelled by the commodification of the genetic material of disenfranchised minority groups, who are more likely to bear the brunt of negative impacts of these technologies.

Indigenous peoples are typically wary about genetic-genealogical technologies. A fundamental reason for this is that the way of life for many Native Americans and Alaska Natives, especially those with federally-recognized sovereign status, is dependent on their political designation as an entity – a status that rests on specific *ancestral* criteria. These policies render proof of ancestry a necessity to access resources for their communities – and one that is under constant threat of exploitation, as shown by the US federal government's decision to threaten revocation of the Mashpee Wampanoag tribe's sovereignty in 2018.¹¹ This is something that is unique to Indigenous peoples, setting them apart from other ethnic or minority group in the US, a fact that is true for other postcolonial societies where Indigenous peoples have been accorded special rights and statuses.

In this respect, it is important to challenge both the right of companies to *gift* communal ethnic identities to customers, and the power of DNA to legitimize such identity claims. As Hina Walajahi, David R. Wilson, and Sara Chandros Hull have commented, DTC companies make promises about the “interchangeability of ancestral and personal identity,” setting up a causal relationship between genetic heritage and social identities. Backed up by a public faith in science and scientific authority, consumers use these tools to make statements about their own identities, believing them to be validated by genetic science.¹² In most instances, however, identity is best thought of in terms of *making* relationships, not *having* essential substances such as DNA. As Kim TallBear has asserted, ethnic belonging is “not just a matter of what you claim, but [...] of who claims you.”¹³

In which ways can the positive aspects of this phenomenon be conserved – for instance, its propensity to broaden conceptions of relatedness, and its utility for investigating historical injustices – while protecting those whose rights and sovereignty may be threatened by this economy? An increased focus on DNA as a means to reconstruct genealogical relationships, rather than on the production of genetic *ethnicity* reports, could represent a positive step away from the commodification and geneticization of minority identities. While DNA ancestry testing is not always more informative than genealogical research for answering certain questions about the past, genetic *relative-matching* features can be valuable for finding biological kin when traditional documentation is scarce or lacking, for instance in cases of adoption or forced familial separations. Yet these technologies also pose particular ethical issues.

2 Whose DNA is it?

The very biological interrelatedness that DNA testing uncovers, which forms the great attraction of DNA testing for family historians, means that one individual's decision to upload their DNA to *relative matching* platforms may simultaneously impinge on others' rights to privacy. This issue has been brought under scrutiny recently in connection with the use of third-party DNA-matching websites like GEDmatch to solve police cold cases, without the informed consent of the users of these platforms. While solving crimes clearly counts as a positive use of these technologies, there are concerns that such practices could be used to target vulnerable communities or to reinforce racial profiling.

The best way for people to make decisions about whether to contribute their DNA for any purpose – for DTC ancestry testing or participation in a research study – is for them to understand all of the risks to privacy, not just for themselves but also their family members. However, there is a severe lack of education and information in this regard. Even informed consent forms that individuals sign prior to participating in a genomic research study speak only to risks to the person and usually do not include language regarding group risk.

Indigenous groups, on the other hand, have a more communitarian understanding of ethics: they regard DNA as not solely theirs to give. While scientists and DNA testing companies have tended to regard this communitarian model of consent as a hindrance to gaining genetic samples, adopting this standard more widely may help protect the rights of those who do not wish to be identified by these services.

3 What can scientists do?

Above all, achieving more responsible practices requires substantive change from within the industry. In recent years, many companies have focused on improving the precision and detail of their genetic *ethnicity* estimates, which constitute the greatest draw for new customers. Due to US Native American tribes' sovereign power to regulate genomics research, companies like 23andMe and AncestryDNA have sought to improve their coverage of Indigenous American populations by collecting DNA from Central and South American groups, who do not have the same regulatory mechanisms governing community-based research. While these companies claim to respect the cultural, religious, and national autonomy of Indigenous groups around the world, the use of these samples to market *Native American ancestry* – thereby equating Indigenous ancestry from one part of the Americas with the other – only reaffirms Indigenous peoples' fear of biocolonialism.

As well as monetizing datasets to private companies, these businesses also cultivate partnerships with academic and non-profit institutions. One possible way to advocate for change is for the scientists who utilize these technologies to be cognizant of the implications of their research and the statements that they and others make about their work. The fact that DNA is becoming increasingly mired in ethical and legal issues means that scientists must become vocal advocates for protecting those whom their research potentially affects. Even if scholars cannot effectively influence commercial genetic ancestry testing, they can ask policymakers to develop policies that address these concerns or choose not to partner with them as academics.

Notes

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