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Nita Farahany, Saheel Chodavadia & Sara H. Katsanis

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Guest Editorial



Ethical Guidelines for DNA Testing in Migrant Family Reunification

Nita Farahany, Duke University School of Law Saheel Chodavadia, Duke University Sara H. Katsanis, Duke University

In the summer of 2018, U.S. Customs and Border Protection Officers removed more than 2600 migrant children from their families at the United States-Mexico border (Gonzalez, Republic, and Gomez 2018). The rationale behind the separations ranged from the criminal prosecution of illegally entering adults accompanying the children to uncertainty over the true relationships between the adults and children. By July, the U.S. government announced its intent to use genetic testing as a way to ascertain the alleged biological relationships between the children and accompanying adults (Buncombe 2018). Suddenly, questions about whether and what form of genetic testing should be used in this context, whether and what privacy protections should apply, and the role of genetic testing in immigration became subject to international debate, drawing in bioethicists, geneticists, and practitioners alike. We believe that voluntary genetic testing in immigration can serve a useful function, but that ethical guidelines for its implementation are urgently needed.

The public debate this past summer became muddled in part because of the various rationales that were advanced by different stakeholders to justify the use of genetic testing of immigrants in this context. Jeff Sessions, for example, in his role as then-Attorney General of the United States, proposed DNA testing at the border to detect human trafficking (Mint Press News 2018). Others advocated for DNA testing at the border as a way to reconnect displaced families. When the Trump administration by Executive Order rescinded its parent-child separation policy (Trump 2018), genetic testing companies such as 23andMe and MyHeritage offered their personal genome services to separated families to help with reunification. Thermo Fisher Scientific also offered access to its reagents and instrumentation (Thermo Fisher Scientific 2018). These offers were promptly rejected by organizations working with separated migrant families, citing concerns over human rights and the ability to obtain meaningful informed consent (Silva 2018). By July 2018, Health and Human Services Secretary Alex Azar announced plans to use DNA tests for reunification of separated families (Rhodan 2018).

Azar's announcement follows nearly two decades of U.S. policy using DNA testing as evidence of immigrant family relationships in both refugee programs and simple visa petitions (Cronin 2000; Khatri 2006). In July 2000, Michael D. Cronin, then Executive Associate Commissioner of the United States Citizenship and Immigration Services (USCIS) (2018), formalized DNA testing to verify parentage as part of the family reunification process in immigration (Cronin 2000). In 2008, in response to reports of relationship fraud among petitioners in the Priority 3 (P-3) refugee visa access program, USCIS undertook a DNA pilot study to examine the prevalence of fraudulent relationship claims among resettled West African refugees (Bureau of Population, Refugees, and Migration 2008). The study found a significant percentage (16%) of petitioners to be unrelated to their family members, and even more (45%) refusing the DNA tests to establish their genetic relationship (Esbenshade 2010). While some argued that these results were inflated due the absorption of the "no-show" population into the fraudulent category (Holland 2011), the findings are the motivating rationale for requiring DNA evidence in the P-3 visa program (Bureau of Population, Refugees, and Migration 2008).

Since the 2000 memo, DNA testing among nonrefugee petitioners has become more commonplace in visa applications for family reunification. A petitioner can opt to use DNA testing if no other legal proofs of identity or relationship to the claimed relative within the United States exist. Immigration officers may also suggest petitioners submit genetic evidence in review of the

Address correspondence to Nita Farahany, Duke University School of Law, Duke Initiative for Science & Society, Duke University, Durham, NC; 27708, USA. E-mail: farahany@duke.edu

petitioner's claims of a biological relationship (Barata et al. 2015), but in accordance with U.S. immigration laws and regulations in the Immigration and Nationality Act (INA) and Title Eight Code of Federal Regulations (8 CFR), USCIS cannot require DNA testing when evidence is insufficient (USCIS 2018). The Department of State's Bureau of Consular Affairs describes the process as entirely voluntary (Bureau of Consular Affairs 2018), with the burden of expense on the applicant.

When the government announced its intentions to use DNA tests in a similar manner for migrant family reunification this past summer, the public reaction was swift, negative, and often confused (Richards 2018). Media reports were inconsistent, with scant facts on whether the government would be using commercial consumer genetic tests, using commercial immigration DNA tests, or conducting DNA tests itself. It was unclear whether DNA data would be included in the federal database run by the FBI (CODIS), or whether the Department of Homeland Security would be creating its own database to store the information collected. Few details emerged to address the confusion, even after Congressional representatives demanded specific answers about the program (Speier 2018).

It is curious, however, that the public and policymakers reacted so strongly to use of DNA in this particular instance, since DNA testing has been used now for years in immigration processes. Were these critics simply unaware of the precedent use of genetic information in immigration? Or was the negative reaction aimed instead at the political factors that were already overwhelming the media and the public dialogue about the separation of families?

We believe there are sound arguments for the use of genetic information in immigration but that there are ethical concerns that must be addressed if its use is to become more widespread, particularly in vulnerable populations. While the pilot study in West Africa may have overestimated the reports of fraud in immigration (Dove 2013), fraud undoubtedly exists where petitioners make false biological claims to gain illegal entry into the United States. And although we are unaware of any reports of human trafficking during this most recent immigration crisis at the United States–Mexico border, child trafficking through false claims of relationships remains an issue of worldwide concern (Solf 2012).

We believe the following ethical concerns should be deliberated upon, have best practices developed for, and be swiftly addressed in guidelines that should govern the collection and use of genetic testing information for immigration in the United States.

Limit DNA testing to necessary cases. DNA testing should be limited to "when necessary to verify a legitimate, good-faith concern about parentage or to meet a reunification deadline" (United States District Court Southern District of California, Order Following Status Conference, 2018), and completed promptly if a removed parent seeks to be reunified with his or her child (United States District Court

Southern District of California, Order Following Status Conference, 2018). Testing is unnecessary if parent–child relationships can be proven in other ways, such as through authenticated birth certificates or other documentation. Limiting DNA testing to address good-faith concerns will avoid collecting sensitive information in contexts where it is unnecessary, and avoid stigmatizing families that have been established nonbiologically.

Do not stigmatize nontraditional families. A DNA test cannot verify family relationships; it can confirm only biological ones. If genetic information becomes the sole evidence in immigration decisions, this will stigmatize families constituted without traditional biological connections. Furthermore, conducting DNA testing without providing adequate information to families regarding potential consequences can seriously damage familial relationships. Testing for a biological relationship may reveal misattributed parentage or hidden social adoptions. This revelation could disintegrate family bonds and psychologically break a child's trust in his or her parents and adults in general (Barata et al. 2015). Additionally, one of the primary rationales behind DNA testing is to detect child trafficking. However, biological relatives traffic children too, so the notion that children are only safe with biological family is misleading. Thus, the agencies responsible should ensure that proper information is provided to families regarding DNA testing and qualitative forms of family assessment are conducted to ascertain risk of trafficking.

Concerns about consent. Many of the bioethicists who voiced their opposition last summer focused on the inability to consent unaccompanied children for DNA testing (Weise, Suppe, and Gomez 2018). This is an area ripe for further ethical debate and discussion. Informed consent is a fundamental tenet of medical testing, but it is unclear whether DNA tests for identity should be regarded the same as medical tests, particularly when they are limited in scope to ascertain biological relationships and used solely for forensic purposes. Moreover, consent is required for immigration DNA tests under American Association of Blood Banks (AABB) guidelines, but can currently be given by whomever has legal custody of the child, which would be the Office of Refugee Resettlement (ORR) in the case of migrant children in custody (American Association of Blood Banks 2018). Whether consent to genetic testing for children is appropriately delegated to ORR requires further deliberation and discussion. Complicating the issue of consent is whether the decision to undergo testing can be made without coercion, particularly if reunification for parents and children is conditioned on genetic testing (Weintraub 2018). Determining the right balance between informed consent, protecting a child against fraud or trafficking, and enabling reunification must be addressed in guidelines governing DNA testing in immigration.

Cultural barriers. One often-overlooked ethical concern regarding DNA testing in families is the cultural aversion of families at the United States-Mexico border. especially Latino families, to DNA testing. This requires better education, dissemination of information, and culturally sensitive discussions of DNA testing. An empirical study of Latino communities about their awareness and attitudes about genetic testing revealed mistrust about how their genetic information could be misused in the future, such as to conduct unauthorized research or to discriminate against them in life or health insurance coverage decisions, or even whether stored genetic information could be used to clone a person or group of persons (Hamilton et al. 2016). Overarchingly, the cultural concern is that genetic information is akin to the most private of information disclosable to a party, and without knowing what that information will be used for, many families are extremely averse to participating in DNA testing, even if it means the reunification of family (Richards 2018). These concerns underscore the need to have clear limitations on the use of genetic information collected for immigration purposes, and to have clear disclosure about those limitations to tested individuals.

Limitations on use. Specific guidelines can mitigate the risks and maximize the advantages of DNA testing in immigration. UCSIS guidelines should be strengthened to accommodate for the influx of DNA and biometric data of nonresidents and noncitizens and limit its use for purposes of resolving immigration decisions and not stored for future purposes.

Limit testing to informative genomic markers. Currently, DNA testing for immigration is conducted by obtaining DNA from the child and alleged parents and analyzed in a laboratory for commonalities and differences. Specific guidelines should be established to ensure that only the necessary number of genomic markers are tested to prove parentage, or kinship. The exact number of genomic regions necessary to do so will vary based on the nature of the kinship to be established, but limiting the scope of testing will help assuage concerns about misuse of genetic information.

Destroy source specimens and DNA samples after use. Genetic samples collected and tested for immigration purposes should be destroyed after their intended use has been concluded. Considering that one of the primary concerns of both bioethicists and families involved in the reunification process is the collection, storage, and usage of genetic information after reunification, one of the most salient ways to alleviate the concern while still fulfilling the purpose of DNA testing is to simply destroy the samples after use and remove DNA data from any related databases. If the authenticity of the DNA test is later contested, confirmatory tests can be run from fresh samples.

Establish clear privacy standards. The off-books repurposing of DNA data to assist local police departments in criminal investigations should be limited through strict guidelines regarding transfer of genetic information from collection point to testing point (Ram 2018). Furthermore, a transparent record of the movement of DNA data and

case-specific information should be provided to the families who have been tested, to ensure the families are aware of the status of their data at all times.

For a longer term solution to identification at the border, the use of DNA in the family reunification process requires the engagement of bioethicists, academics, legal professionals, human rights advocates, nongovernmental organizations, and interested stakeholders who focus on migrant child placement to work together to evaluate the role of biometrics and DNA in the immigration process. These longer term solutions should focus on the development of international guidelines that ensure that respect for individuals, data privacy, and integrity are maintained throughout the family reunification process.

Lastly, new and current technologies such as rapid DNA analysis could be incorporated to maximize the efficiency of the process, and blockchain technologies could advantage security of data transfers. Taking advantage of and developing standards to adopt advanced technology would prove beneficial for long-term sustainability and efficiency of the process.

Overall, the current migration crisis is an opportunity to open a dialogue around how to balance national security and the protection of vulnerable children and immigrant populations. Scientists, legal scholars, and bioethicists can correct misunderstandings of how genetic information has been, is being, and will be used for this and future migrant crises. We advocate for the right science at the right time that is the most useful and least invasive, alongside policy recommendations to enact systems to manage genetic data and the family reunification process in general.

CONFLICTS OF INTEREST

Nita Farahany serves on the Ethics Advisory Board for Illumina, Inc., and the Scientific Advisory Board for Helix, Inc., both genetic testing companies.

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