

The DNA of Roma People Has Long Been Misused, Scientists Reveal

An op-ed in Nature calls for higher ethical standards in the usage and analysis of genetic information from the Romani, a marginalized group in Europe.



A Romani community near Kezmarok, Slovakia. An analysis of 100 years of scientific papers, most published in the last 30 years, contained “shocking surprises.”

By Sabrina Imbler

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For decades, geneticists have collected the blood of thousands of Roma people, a marginalized group living in Europe, and deposited their DNA in public databases. The ostensible purpose of some of these studies was to learn more about the history and genetics of the Roma people.

Now, a group of scientists has argued this research, which has made the Roma the most intensely studied population in Europe over the past 30 years in forensic genetic journals, is rife with ethical issues and may harm the Romani people.

For five years, a team of researchers in Germany and the United Kingdom pored over more than 450 papers that used the DNA of Roma people to understand how geneticists and other scholars obtained, interpreted and shared that genetic information. Their analysis, published Wednesday in an op-ed in the journal [Nature](#), revealed many instances of clear misuse or questionable ethics.

In 1981, when scientists in Hungary sampled the blood of Roma people incarcerated in Hungarian prisons, they classified prisoners as Romani based solely on their appearance, which the authors of the new paper argue is unscientific. In 1993, another group sampling Romani DNA concluded that there were three distinct ethnic groups in the country, drawing a line between “the genuine Hungarian ethnical groups” and “Jews” and “Gypsies” — a research premise the authors of the new paper argue was racist. In the 2000s, papers on the genetics of Roma people still referred to the group with the outdated term “Gypsy,” which is considered a slur, or with pejorative terms such as “inbred” or “consanguineous.”

“This is an important contribution to the ongoing conversation about ethical issues in genetic research,” said Deborah Bolnick, an anthropological geneticist at the University of Connecticut who was not involved with research. Much of this conversation has taken place in North America and Australia, not Europe, she added.

“The unethical practices described here are unfortunately very familiar and not a surprise,” Dr. Bolnick added.

“It’s just horrifying,” said Ethel Brooks, a Romani scholar and chair of the department of women’s, gender and sexuality studies at Rutgers University in New Jersey. “But of course, it’s all things we’ve known and suspected.”

The analysis spanned papers published between 1921 and 2021, most of which were published in the last 30 years. The earlier papers included “so many shocking surprises,” said Veronika Lipphardt, a science historian at the University of Freiburg, Germany, such as the samples taken from incarcerated Roma people and many instances of racist language.

“Many didn’t believe us,” Dr. Lipphardt said, “because it was simply so hard to believe” that such practices were “ongoing.”

In Europe, the Roma people have been oppressed for hundreds of years and still experience significant discrimination. During the Holocaust, Nazis collected blood samples from Roma people imprisoned in Auschwitz and murdered hundreds of thousands of Roma and Sinti people. In 2015, the Slovakian government defended its practice of segregating Roma children in schools, falsely citing “mild mental disabilities” tied to “high levels of inbreeding” in Romani communities.

“The slip from genetics to eugenics is one that can happen quite easily,” said Dr. Brooks.

Mihai Surdu, a visiting sociologist at the University of Freiburg and an author on the paper, conceptualized the project when he was writing a book on the Roma people. While searching for publications with the words “Roma” or “Gypsies” in the titles, Dr. Surdu found what seemed like an outsized number of studies on Roma DNA — nearly 20 papers.

When Dr. Surdu wrote to Dr. Lipphardt in 2012 about this phenomenon, he was unsure if it was a fluke. But over the course of their study, the researchers uncovered more than 450 genetic papers with Roma subjects.

With funding from the German Research Foundation, the two researchers expanded the team to include scholars from diverse disciplines, and also consulted with Anja Reuss, a spokesman for the Central Council of German Sinti and Roma, an advocacy group based in Heidelberg.

They found that many studies did not adequately seek consent from the people they sampled, if they secured consent at all. Some studies cited oral consent, but “no one knows what the consent really was,” said Peter Pfaffelhuber, a mathematician at the University of Freiburg and an author on the paper.

“In a way, our consent is never deemed necessary because we are not deemed able to give our consent,” Dr. Brooks said.



A Roma settlement at the Lunik IX quarter of Kosice, Slovakia.

In 2010, the main journal in the forensic genetics community, *Forensic Science International: Genetics*, adopted ethical requirements including informed consent. But although some papers published more recently state they were conducted with the written consent of all participants, they include DNA from earlier papers that was collected with murky procedures. “You cannot assume that consent from 30 years ago is still valid, that it can be extended forever for all possible uses,” Dr. Lipphardt said.

One 2015 study pointing to Indian origins of the Roma people uploaded their amassed DNA data set to two public databases that law enforcement agencies across the world use for genetic references to solve crimes, a purpose to which the original participants likely did not consent.

Even though much of this DNA was collected decades ago, its presence in public databases poses a present danger to modern communities. The 2015 study uploaded Roma DNA to the Y-STR Haplotype Reference Database, or YHRD, a searchable worldwide collection of anonymous Y-chromosome profiles that has become a crucial and contested tool helping police solve crimes. In YHRD, the national database for Bulgaria lists 52.7 percent of its data sets as “Romani” even though Roma people only make up 4.9 percent of the country’s population. If a minority population is disproportionately represented in a DNA database, this could create bias against “suspect populations,” some scholars argue. Some of these profiles came from population studies where the researchers thanked police forces for collecting the DNA.

Marginalized groups like the Roma people are subject to increased surveillance and policing because of personal, institutional and cultural bias, said Matthias Wienroth, a social scientist and ethicist at Northumbria University in the United Kingdom and an author on the paper. “The continued use of genetic samples and data from marginalized communities further marginalizes these communities.”

Part of the allure of Romani DNA to geneticists is the assumption that the group has been genetically isolated for hundreds of years. But the authors argue that many researchers rely on biased samples from isolated populations while intentionally excluding data from Romani people with mixed ancestry.

“It was probably the most easy to get the blood samples from these places,” said Gudrun Rappold, a human geneticist at the University of Heidelberg and an author on the paper. “But then to draw conclusions with regard to these millions and millions of Roma people? This is just leading to the wrong conclusion.”

Dr. Surdu added, “They’ve maintained this narrative contrary to evidence.”

These highly sampled, isolated data sets, which often name specific villages, could also endanger the anonymity of individuals, especially those with rare genetic diseases, the authors argue.

To ensure that Romani DNA is used ethically in the future, the researchers proposed four concrete changes. They looked to existing models for ethical DNA use for guidance, such as the Indigenous-led SING Consortium and the ethics code drafted by the San people of South Africa governing the use of their own genome, Dr. Lipphardt said.

The authors recommend forming an international oversight board to investigate the DNA information from oppressed groups that is currently held in public databases, to benefit the Roma and other communities. They also call for more training on the ethics of collecting genetic data from marginalized communities, so that researchers can understand the societal implications of their work.

The authors also ask journals to investigate or retract ethically fraught studies that include Romani DNA, citing Springer Nature’s recent retraction of six papers using DNA from Chinese minority ethnic groups.

Finally, the researchers call for more conversations between scientists and participants, so that Roma people can learn about the benefits and risks of donating DNA.

Most genetic studies of Roma DNA either seek to identify the origins of the Roma people in India or pinpoint their unique genetic mutations. But few studies aim to benefit the health and welfare of the Romani community, many of whom live in segregated settlements with less access to resources like housing and education. Dr. Lipphardt cautioned that even if genetic studies on Roma DNA led to treatments for rare diseases, there was no guarantee that those therapies would be made easily accessible to Roma people.

The authors suggest scientists collaborate with and train Roma people to pursue research questions relevant to their communities. Only one paper of the 450 they examined mentioned community involvement, including training Roma doctors, nurses and midwives and conducting educational health screenings.

But Dr. Surdu viewed this involvement as insufficient since the researchers did not let Romani concerns guide the research or engage the larger community, but only recruited Roma mediators to carry out a planned study. He added that he sees this access to health care and social services as a basic human right. “Informed consent for samples collected for genetic research should be fully voluntary,” Dr. Surdu said.

These entrenched barriers to education are part of the reason there are fewer Romani scholars, Dr. Brooks noted. She said she felt excited about the prospect of Romani people having oversight of their DNA, both in the context of outside research and their own families.

“To really open up space for these kinds of discussions within marginalized communities?” Dr. Brooks said. “It would be a scientific revolution.”