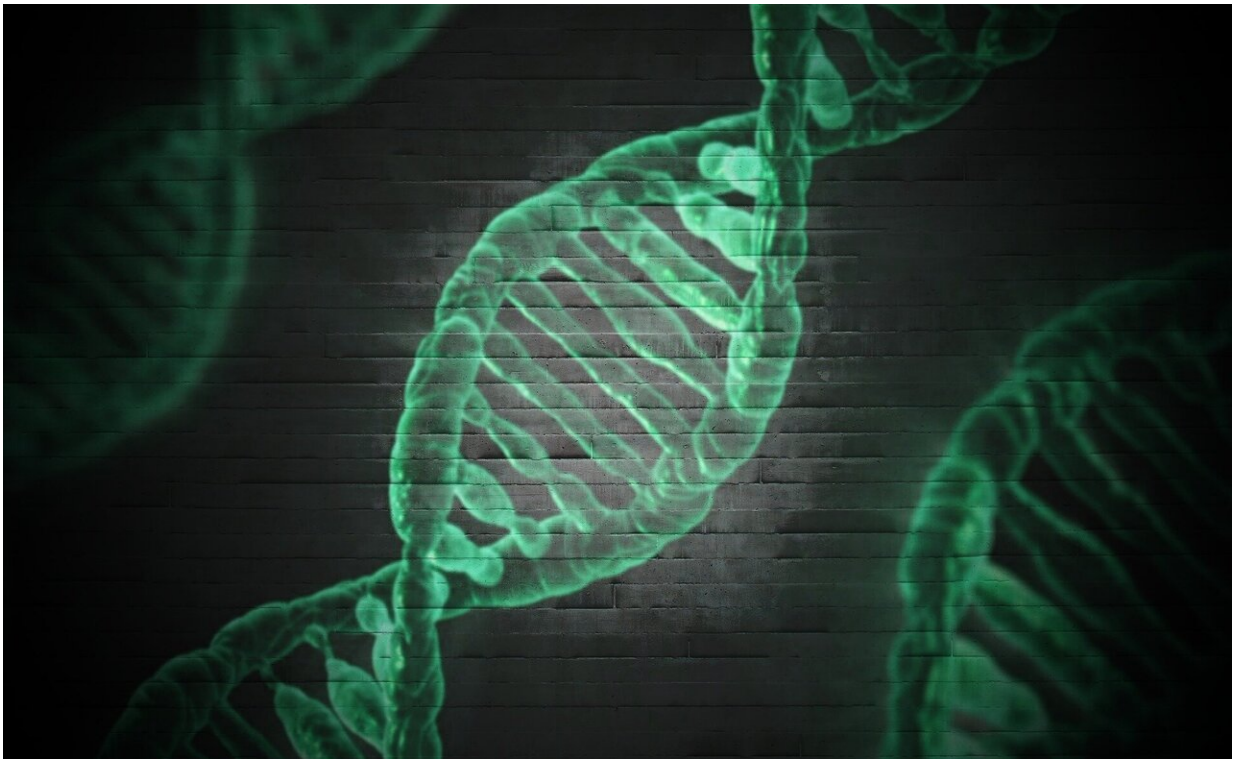


# Lack of awareness of the sensitivity of DNA data

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In both ethical and scientific respects, Roma population groups are treated inappropriately in DNA databases and in genetic studies—potentially with consequences for investigations that draw on forensic genetic databases: this was the conclusion of Prof. Dr. Veronika

Lipphardt and her colleague Dr. Mihai Surdu from the Chair of Science and Technology Studies at the University of Freiburg in two specialist publications which they have now released as preprints—one with the involvement of Heidelberg-based human geneticist Prof. Dr. Gudrun Rappold.

As Lipphardt and Surdu explain, since roughly the start of the 1990s, DNA data has been gathered from Roma in Eastern Europe and on the Iberian peninsula. Major international research teams from Eastern and Western Europe analyze and publish these data in journals covering various genetic disciplines—there have been 45 forensic genetic publications on this alone since 1990. "Forensic geneticists have regarded the Roma as a genetically interesting population group for decades. Some forensic genetic databases contain proportionally far more DNA from them than from other population groups," says Lipphardt.

The data collectors start from the assumption that the Roma are a clearly-definable, genetically-isolated group that originates from India, a misapprehension with wide-ranging consequences, because the researchers only search out subjects who come from isolated communities or villages. But isolated villages such as mountain villages are not representative of larger [population groups](#), just look at the people of Switzerland: after all, the rest of the population does not live in isolation. Likewise, in past centuries the Roma did not live in isolation and they have forebears from many different regions, above all from Europe. Presenting them as an isolated, alien group can contribute to stigmatization and exclusion, the research team argues.

Lipphardt and Surdu also refer to internationally-recognized ethical standards for genetic research in documenting problematic aspects of the use of DNA data from Roma in forensic contexts. They show that two crucial ethical requirements are rarely met: informed consent from all

subjects, and the backing of studies and data gathering by an ethics committee. In addition, Lipphardt and Surdu note that several forensic genetic studies that use DNA data from Roma have co-authors who are institutionally closely linked with police, investigative or military forces. This finding indicates a risk that conscious or unconscious stereotypes and discrimination may color forensic [genetic studies](#) and investigations.

"What we have observed in the available sources can be described as a wide-ranging lack of transparency that indicates many forensic geneticists lack awareness of the ethical sensitivity of DNA data from Roma," Surdu sums up. "These results should be seen against the background of the violent history of bioscience research on Roma and ethnic profiling by police forces." The publications contain proposals for improving the situation of Roma as well as ethical standards in forensic genetics: these include a sustained institutionalized dialog between researchers and Roma, a joint review of [ethical standards](#), and the involvement of humanities and social scientists in the review process.

**More information:** Lipphardt, V./ Rappold, G./Surdu, M. (2020): Representing vulnerable populations in genetic studies: The case of the Roma. [DOI: 10.13140/RG.2.2.13286.04165](https://doi.org/10.13140/RG.2.2.13286.04165)

Lipphardt, V./Surdu, M. (2020): DNA Data from Roma in forensic genetic studies and databases: Risks and challenges. [DOI: 10.13140/RG.2.2.16641.48484](https://doi.org/10.13140/RG.2.2.16641.48484)

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