## Ethical Challenges in Romani Studies<sup>1</sup>

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Ladies and Gentlemen, Dear Colleagues, Members and Friends of the Gypsy Lore Society,

Since my election as President of GLS, which also comes with the honor of opening our regular meetings in one of the countries of our active members, when preparing my opening speech, I try to highlight the most current topics or methodological approaches, or point out the latest trends not only in our common cross-disciplinary field of Romani studies. Thus, in Prague 2021 I addressed reflection on the COVID-19 topic and its impact on the general population all over the world and, in particular, the people who are members of ethnic, social, cultural, or other minority groups that, for various reasons, suffer many times, or suffer more than the average population due to structural inequalities and other systematic failures, in Belgrade 2022 On Postnormality and the Science and necessity of a *reflective turn*, and in São Paulo in 2023 I highlighted challenges of Romani Studies in digital era.

This time, I would like to draw your attention to a frequently overlooked or sidelined topic, that is simultaneously strongly debated in our academic circles (including at some of our previous conferences) which I believe is absolutely crucial in Romani studies—research ethics, ethical research conduct, and scientific integrity.

The topic of ethics is still not perceived as an integral part of our thinking about the research problem, yet it is essential in constructing the research design, and some authors even claim that it largely overlaps with methodology (e.g., De Koning et al., 2019).

My focus on ethics as a key element that Romani studies should dedicate special attention to was inspired by my discussions with the PhD students at our institute during the spring and summer. Thanks to those conversations, I realised that many of them encountered both common and uniquely specific challenges, requiring them to devise sensitive and innovative solutions. Their supervisors and the members of the Ethical Committee found themselves in a similar position—squeezed between their honest attempt to deliver the most relevant research and collect the best data for further analysis and interpretation, and their honest attempt to prevent any harm to the interlocutors, communities involved, researchers themselves and the institution responsible for the research. I encourage our PhD students to publish their

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experiences in a joint volume, creating a kind of practical manual for the next generation of students, so they wouldn't have to start from scratch (Kinczer and Zachar Podolinská, Eds., 2024)

While editing the first volume, I understood that an introductory chapter would be appropriate to provide a general overview of the topic. The more I immersed myself in what had previously not been a central focus of my professional interest, the more I became aware of the gap in the formulation of qualitative research guidelines and sensitive ethical conduct awareness.

The text of the introductory chapter eventually expanded into a monograph, under the title *Ethical Challenges in Current Ethnology and Social Anthropology, II.* Part of the volume devoted to ethical controversies and breaching of scientific integrity revealed that in the case of Slovakia, the most significant ethical controversies in the 21<sup>st</sup> century happened in the field of Romani studies (Zachar Podolinská, 2024).

While writing the text on ethics in qualitative research, I also began preparing the ethical design of the RELIROMA project focused on *Research of Religiosity, Spirituality and Non-Religiosity among the Roma in Slovakia*<sup>2</sup> project, in the framework of which our team initiated discussions on how to implement a sensitive research design in Romani communities. Our field research is challenging in several respects, as we collect personal testimonies of journeys *in* our out of religion, which include stories of conversion, personal miracles, spirituality, as well as deconversion, disappointments, loss of faith, and trust in God and church as an institution. Additionally, we encounter distancing from traditional religiosity and spirituality within the local community, as well as from non-preferred ethnicity and identity.

These stories are shared in good faith, in situations of absolute trust in the people present in conversations, particularly the researcher, from whom understanding, acceptance, and sometimes even explanations and psychological relief are expected. These situations generate not only a unique kind of *knowledge*, but also *understanding*, in which both the "participant" and the "researcher" become integral parts.

Informed consent alone does not capture the complexity and intimacy of these situations, just as anonymising locations or interlocutors is often insufficient, and, sometimes and sometimes even harmful (making impossible to verify and further use the results. In many times informants even insist on the publication of their full names and disagree with unnaming of locality. To create the most sensitive and up-to-date ethical design possible—while avoiding numerous pitfalls associated with qualitative research on sensitive issues in vulnerable communities (e.g., Sriram et al., Eds., 2009;

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<sup>&</sup>lt;sup>2</sup> Project APVV-22-0389 (RELIROMA) "Research of Religiosity, Spirituality and Non-Religiosity among the Roma in Slovakia". See: https://uesa.sav.sk/en/projects/national/research-of-religiosity-spirituality-and-irreligiozity-among-the-roma-in-slovakia/.

Aldridge, 2014)—we must learn not only from the ethical controversies in Romani studies but also from best practices in current ethnology and anthropology worldwide.

Ethic and minority communities present a unique challenge, necessitating a balance between respecting *indigenous knowledge systems* and adhering to *global ethical norms*. Under these conditions, informed consent processes should be *culturally sensitive* and considerate of the participants' and communities' worldviews.

Informed consent must be adapted to cultural norms which may include considerations for collective decision-making practices within Roma communities. Researchers must be attentive to cultural nuances in communication and consent, ensuring that participation is voluntary and based on a clear understanding of the research purpose and procedures (Roman et al., 2012).

Researcher should actively involve community members in the research process, fostering a partnership that leverages local knowledge and promote shared decision-making (Miranda et al., 2019).

While conducting research in Romani communities, ethical dilemmas may arise when balancing community traditions with mainstream moral and cultural norms and forms of behaviour (Condon et al., 2019). Therefore, researchers must engage with community leaders and key-voice members to identify acceptable practices that align with both ethical research standards and community values.

In this regard, it can be stated that along with the growing need for the development and use of increasingly sensitive ethical research designs, the pressure for their formalization is also increasing, while the bureaucracy associated with their implementation is growing. We are also witnessing the *monetization* (the requirement to adhere to formal ethical rules to obtain research funding) and *commodification* of research data (trading with depersonalized data or providing it to third parties). This causes significant problems, especially in the social sciences and humanities, which are strongly felt in Romani studies as well.

The first decade of the 21<sup>st</sup> century, in Romani studies, reflected the trends in discussions about ethics in ethnology and anthropology. That is, our authors also reflected the highlights of this decade, which were undoubtedly *decolonization* (e.g., Asad, Ed., 1973; Said,1978; Harrison, Ed., 1997; Bolles, 2023); or reflections on various forms of colonialism present in social science research in the Second and Third World countries. The discussion also registered appearance of worrying phenomena such as "woke culture" or "cancel culture" (e.g., Clark, 2020; Norris, 2021), which in our context have been transformed not only into discussions on *gypsyism* and *anti-gypsyism*, but also into the themes of racism and accusations of racism, which can take the form of cancel culture and contribute to authorial self-censorship or silence on problematic aspects of the studied phenomena (e.g., Williams, 2016).

At the close of the second decade of the 21<sup>st</sup> century, Romani studies also has to deal with the challenges of implementing GDPR rules. In the qualitative field so-called post-GDPR ethnology was formed, where authors critically reflect on the introduction of strict ethical protocols into anthropological research, which are characteristic for medical research. Similarly, they criticize the formalization of ethical standards and the adoption of increasingly extensive ethical guidelines, which qualitative researchers must follow. Many point to the so-called *audit culture*, where the ethics committees of various institutions, which approve the ethical designs, tend to primarily protect the institutions and tend to negatively assess ethical designs in challenging environments.

In the journal *Social Anthropology/Anthropologie Sociale*, in a discussion Forum, Peter Pels (2018) pointed out that the process of generating our data arises in *co-production*. Research participants cannot be simply removed from the post-processing by signing informed consent, as subsequent depersonalization (anonymization of participants, or their pseudo-anonymization, or locations) is sometimes imperfect and protects the institutions more than the actual actors.

Depersonalization is also completely contrary to the essence of our disciplines, which are about specific people, about personal human stories and trajectories, which should not be rewritten or censored because it interferes with the identity of the stories, but also the identity of the people, and is likewise a violation of scientific integrity.

Current trends and dilemmas of post-GDPR anthropology (Yuill, 2018), which is moving towards the *deformalization* of ethics and the defense of the *unique nature* of qualitative research (e.g., Castillo, 2018; Sleeboom–Faulkner and Simpson, 2018), should also be reflected in Romani studies. Our ambition should be not only to sensitize our approaches to constructing ethical designs in Romani communities, but also to reflect on the limitations of the methods we use, including participatory and empowering designs.

Since it is probably never possible to completely eliminate the impact of our work (negative or positive alike), which can be caused by our mere presence and any interaction with people from the community, it is all the more important to honestly reflect on these impacts and strive to eliminate their possible negative consequences in advance. The path that leads to sensitizing the researcher, to taking responsibility for research data throughout its entire lifecycle, and to critically reflecting on inevitable mistakes that cannot be fully addressed by any detailed or context-embedded ethical codes, is the path that modern researchers in Romani studies should follow (Zachar Podolinská, 2024). On this path, I wish us all success, patience, and perseverance not to give up in difficult situations and to be guided by the most sensitive internal moral compass.

## References:

- Asad, T. (Ed.) (1973). Anthropology and the Colonial Encounter. New York: Humanities Press.
- Bolles, L. A. (2023). Ethnography at its edges. Decolonizing Anthropology: An Ongoing Process. *American Ethnologist*, *50*(3), 519–522. DOI: https://doi.org/10.1111/amet.13199.
- Castillo, R. C. A. (2018). Subverting "formalised" ethics through mainstreaming critical research ethics and responsive review process. *Forum. Social Anthropology/Anthropologie Sociale, 26*(3), 405–6. DOI: https://doi.org/10.1111/1469-8676.12526.
- Clark, M. D. (2020). DRAG THEM: A brief etymology of so-called "cancel culture". *Communication and the Public*, 5(3-4), 88–92. DOI: https://doi.org/10.1177/2057047320961562.
- Condon, L., Bedford, H., Ireland, L., Kerr, S., Mytton, J., Richardson, Z., & Jackson, C. (2019). Engaging Gypsy, Roma, and Traveller Communities in Research: Maximizing Opportunities and Overcoming Challenges. *Qualitative Health Research*, 29(9), 1324–1333. DOI: https://doi.org/10.1177/1049732318813558.
- De Koning, M., Meyer, B., Moors, A., & Pels, P. (2019). Guidelines for Anthropological Research: Data Management, Ethics, and Integrity. *Ethnography*, *20*(2), 170–174.
- Harrison, F. V. (Ed.) (1997). *Decolonizing Anthropology: Moving Further toward an Anthropology for Liberation. American Anthropological Association.* Arlington, Virginia: Association of Black Anthropologists, American Anthropological Association.
- Kinczer, M., & Zachar Podolinská, T. (Eds.) (2024). *Etické dilemy v súčasnej etnológii, I.* Bratislava: ÚESA SAV, v. v. i. DOI: https://doi.org/10.31577/2024.9788097443450.
- Miranda, D.; García-Ramírez, M., Balcazar, F., & Suarez-Balcazar, Y. (2019). A Community-Based Participatory Action Research for Roma Health Justice in a Deprived District in Spain. *International Journal of Environmental Research and Public Health*, 16(19), 3722. DOI: https://doi.org/10.3390/ijerph16193722.
- Norris, P. (2021). Cancel Culture: Myth or Reality? *Political Studies Review*, 71(1), 145–174. DOI: https://doi.org/10.1177/003232172110370.
- Pels, P. (2018). Data management in anthropology: the next phase in ethics governance? *Forum. Social Anthropology/Anthropologie Sociale*, 26(3), 391–396. DOI: https://doi.org/10.1111/1469-8676.12526.
- Roman, G., Enache, A., Parvu, A., Gramma, R., Moisă, Ş., Dumitraş, S., & Ioan, B. (2013). Ethical issues in communication of diagnosis and end-of-life decision-making process in some of the Romanian Roma communities. *Medicine, Health Care and Philosophy*, 16, 483–97. DOI: https://doi.org/10.1007/s11019-012-9425-5.
- Said, E. W. (1978). Orientalism. New York: Pantheon Books.
- Sriram C. L., King, J. C., Mertus J. A., et al. (Eds.) (2009). *Surviving Field Research: Working in Violent and Difficult Situations*. London and New York: Routledge.
- Sleeboom–Faulkner, M., & Simpson, B. (2018) From protocol-based to exploratory research. *Forum, Social Anthropology/Anthropologie Sociale*, 26(3), 404–405. https://doi.org/10.1111/1469-8676.12526.
- Williams, J. (2016). Academic Freedom in an Age of Conformity: Confronting the Fear of Knowledge. New York: Palgrave Macmillan.
- Yuill, C. (2018). "Is Anthropology Legal?". Anthropology and the EU General Data Protection Regulation. *Anthropology in Action, 25*(2, Summer 2018), 36–41. DOI: https://doi.org/10.3167/aia.2018.250205.
- Zachar Podolinská, T. (2024). *Ethical Challenges In Ethnology And Anthropology— The Case Of Slovakia (Late 20<sup>th</sup> and 21<sup>st</sup> Centuries).* Institute of Ethnology and Social Anthropology SAS. Bratislava. DOI: https://doi.org/10.31577/2024.9788097443474.

## Codes of Ethics (selection):

- AAA Statement on Ethics. Principles of Professional Responsibility. https://americananthro.org/about/policies/statement-on-ethics/ [accessed Aug 19, 2024].
- AoIR (2012). Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Committee. Markham, A., Buchanan, E., AoIR Ethics Committee and AoIR general membership. Approved by the Ethics Working Committee, August, 2012. Endorsed by the AoIR Executive Committee, September, 2012. <a href="https://aoir.org/reports/ethics2.pdf">https://aoir.org/reports/ethics2.pdf</a> [accessed Aug 19, 2024].

- EG ASA. Ethical Guidelines for Good Research Practice (March 1999). Association of Social Anthropologists of the UK and Commonwealth. https://www.theasa.org/ethics/guidelines.shtml [accessed Aug 19, 2024].
- CE AAA. Code of Ethics of the American Anthropological Association. Approved February, 2009. https://americananthro.org/wp-content/uploads/AAA-Ethics-Code-2009-1.pdf [accessed Aug 19, 2024].
- GDPR (2016). General Data Protection Regulation. https://gdpr-info.eu/ [accessed Aug 19, 2024].
- Royal Historical Society Statement on Ethics. (October 2020). https://files.royalhistsoc.org/wp-content/uploads/2021/03/18102348/Royal-Historical-Society-Statements-on-Ethics-October-2020.pdf [accessed Aug 22, 2024].
- SACHRP (2013). Considerations and Recommendations Concerning Internet Research and Human Subjects Research Regulations. https://www.hhs.gov/ohrp/sites/default/files/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet\_research.pdf [accessed Sep 8, 2024].