

Contributions to the Public Consultation on Guidelines 1/2026 on processing personal data for scientific research purposes

I. CEIC-UA institutional framework

The Ethics Committee for Clinical Research of the Universidade de Aveiro (University of Aveiro), hereinafter referred to as CEIC-UA, is a collegiate, multidisciplinary, technically and scientifically independent advisory body responsible for the ethical review of research involving human beings or material of human origin, where there is interaction between the researcher and human beings. Its activity is intended to ensure respect for the principles of ethics and bioethics, the protection of human dignity, and the safeguarding of the rights, integrity, trust, and safety of research participants. Its remit includes, among other functions, issuing opinions and assessing the methodological, ethical, and legal aspects of research projects submitted for its appraisal.

In this context, and having regard to the document issued by the European Data Protection Board (EDPB), Guidelines 1/2026 on processing personal data for scientific research purposes, CEIC-UA, qualifies as an interested body for the public consultation on this document, in view of the powers exercised by this Committee in the ethical and legal review of research projects involving human participants and the processing of personal data.

The Committee's activity covers research involving human beings or material of human origin, where there is interaction by the researcher, irrespective of the disciplinary field, methodological approach, or academic or non-academic context in which the research is conducted. In this context, questions frequently arise concerning confidentiality, the protection of participants, the processing of sensitive or special-category data, incidental findings, and the possible disclosure of information to competent authorities.

Guidelines 1/2026 (the Guidelines) therefore have a direct impact on the Committee's activity, particularly as regards the articulation between confidentiality, participant protection, and the limits to the duty to provide information laid down in Article 14 of the General Data Protection Regulation (GDPR). The experience acquired through the ethical review of research has made it possible to identify certain difficulties in applying these Guidelines considering the Portuguese legal order, particularly regarding the management of incidental findings with potential criminal relevance.

II. Subject matter and analysis of Guidelines 1/2026

1. Text addressed by this contribution

“5.4.2.6 In the field of scientific research, the exception from providing information on processing of personal data due to obligations of secrecy might be more prevalent than in other fields of activity. This is because there may be statutory requirements that prohibit researchers from disclosing information on the processing of personal data to preserve the integrity of the research subject¹⁵⁵. Such requirements are particularly important in situations where a research subject discloses sensitive personal data about a third person, the disclosure of which could render the relationship between the research subject and the third person problematic, or even endanger the research subject¹⁵⁶. Example 17: Confidentiality of information on processing of personal data due to statutory obligation of secrecy A research project is carried out on domestic violence and abuse in relationships. The method for gathering data is conducting interviews with potential victims. During such interviews, personal data is gathered on data subjects who might be alleged perpetrators of domestic violence and abuse. While the GDPR would normally require the controller to inform the data subjects who are alleged perpetrators, doing so could endanger the research participants who are being interviewed, i.e. the potential victims. For this reason, the researchers carrying out the interviews are bound by a statutory obligation of secrecy, which the research participants are informed about before the interview. In turn, the rights and freedoms of the alleged perpetrators are also protected by mandatory safeguards provided

for by the relevant law in question. These safeguards include pseudonymization of all personal data, as well as a strict secrecy obligation that prohibits the researchers from disclosing the personal data to other parties, such as law enforcement authorities”.

2. Subject matter of the contribution

This contribution concerns section 5.4.2.6 of the EDPB Guidelines on the processing of personal data for scientific research purposes, in particular Example 17, regarding research projects in the field of domestic violence.

The example used is intended to illustrate the application of the exception provided for in Article 14(5)(d) GDPR, according to which the obligation to provide information to the data subject does not apply where the personal data must remain confidential subject to an obligation of professional secrecy regulated by Union or Member State law, including a statutory obligation of secrecy.

In the case presented, researchers interview potential victims of domestic violence and, during those interviews, collect personal data relating to alleged perpetrators. The EDPB considers that informing those third-party alleged perpetrators about the processing of their data could place the participants in situations of heightened vulnerability, compromise the integrity of the research, and affect the relationship between the potential victims and the alleged perpetrators. Accordingly, it considers the exception provided for in Article 14(5)(d) GDPR to be applicable.

Up to this point, the solution appears legally understandable and proportionate. Not providing information to the alleged perpetrator constitutes an appropriate measure to protect participants, prevent retaliation, and preserve the scientific validity of the study.

However, the example used then states that there is a “strict secrecy obligation that prohibits the researchers from disclosing the personal data to other parties, such as law enforcement authorities”, thereby appearing to impose an almost absolute impossibility of disclosing the data collected, including to competent authorities.

It is precisely at this point that the legal and ethical difficulties arise.

3. Confusion between two legally distinct matters

The example appears to conflate two issues that should be analyzed separately:

- a) the exclusion of the duty to provide information under Article 14 GDPR in relation to alleged perpetrators;
- b) the possible prohibition on disclosing data to public authorities.

The first issue is directly grounded in Article 14(5)(d) and is aimed at protecting research participants.

However, the second issue does not automatically follow from the GDPR and is not a necessary consequence of the exception to the duty to provide information.

The fact that the alleged perpetrator should not be informed of the existence of the processing does not, in itself, mean that researchers are prevented, in all circumstances, from disclosing information to competent authorities where situations of serious risk, imminent danger, or a need to ensure the victim’s safety are at stake.

Example 17 appears to address these two dimensions through a single solution, without adequately justifying that extension.

4. The ethics of disclosure and the protection of participants

European ethical guidance for research in the social sciences and humanities expressly recognizes that confidentiality and secrecy may come into tension with obligations to disclose information to public authorities where incidental findings related to criminality, abuse, or domestic violence arise (European Commission, 2021).

In particular, the European Commission's ethical guidance for SSH (Social Sciences and Humanities) research concedes that criminal activity discovered or witnessed during research may justify disclosure to the competent authorities, even where this entails overriding prior commitments of confidentiality and anonymity given to participants. The same guidance directly addresses situations of domestic violence and recognizes the need for institutional procedures for the management and assessment of incidental findings. Although not legally binding, such guidance constitutes an international ethical reference applicable to research involving human beings and demonstrates that scientific research does not entail an absolute duty of confidentiality (European Commission, 2021).

In this context, institutional procedures concerning incidental findings with potential criminal relevance seek to reconcile the protection of confidentiality and secrecy with the need to effectively safeguard participants and, where appropriate, disclose information to competent authorities in serious situations.

The European Code of Conduct for Research Integrity also establishes that researchers must act responsibly towards research participants and society, respecting legitimately required confidentiality and considering the impact of research on participants and third parties (ALLEA, 2023).

The above-mentioned documents are neither merely anachronistic nor residual. On the contrary, they reflect a current and cross-cutting reality in research involving human beings, particularly in the social sciences and humanities, where qualitative methodologies are used. Interviews may reveal patterns of violent conduct capable of giving rise to complex ethical dilemmas.

Accordingly, European ethical guidance recognizes that tensions may arise between obligations of confidentiality and secrecy, the protection of participants, and the prevention of serious harm. It allows, in certain circumstances, mechanisms for disclosure to competent authorities, even where there is no automatic legal duty to report, without prejudice to mandatory reporting obligations provided for under the Portuguese criminal law framework.

5. Lack of contextualization of risk

Example 17 raises significant ethical difficulties due to the excessively abstract and rigid manner in which it addresses confidentiality in the context of research involving domestic violence.

The example correctly starts from the need to protect participants and to prevent disclosure to the alleged perpetrator from placing the potential victim in situations of particular vulnerability. However, it transforms an exception to the duty to provide information into an obligation of silence towards authorities, including by referring to the impossibility of disclosing information “even to law enforcement authorities”, without providing an adequate framework for assessing the specific seriousness of the situation.

The example does not distinguish between past historical facts, conflicts involving no current risk, continuing abusive conduct, situations involving a serious threat to the integrity or life of participants, the possible involvement of minors, or the urgent need for institutional intervention. As noted above, European ethical guidance does not establish absolute confidentiality in research; rather, it allows for mechanisms of assessment in the face of serious occurrences or concrete risks to participants. Thus, the main ethical difficulty raised by Example 17 does not lie in the protection of confidentiality or in the exemption from the duty to inform the alleged perpetrator, but rather in the formulation of an apparently absolute obligation of secrecy without a case-by-case assessment of the actual danger involved.

Moreover, the protection afforded by the GDPR and research ethics operate on distinct domains. While the GDPR focuses on the lawfulness of processing, transparency, and the safeguarding of data subjects' rights, research ethics also encompasses human dignity, vulnerability, harm minimization, and protection against relevant threats to the physical or psychological integrity of participants. For this reason, confidentiality will frequently coexist with duties to protect the life, physical and psychological integrity, health, and safety of participants, especially in scenarios such as the one depicted in the example under analysis.

6. Need for an approach based on proportionality

Consider the possibility that, during an interview, a participant discloses, for example:

- the existence of serious and current threats;
- a breach of coercive measures;
- stalking or persecution;
- an imminent risk to life or physical integrity.

An unqualified interpretation of confidentiality or secrecy would turn such obligations into a model for perpetuating a situation of vulnerability or risk. Such an outcome would be difficult to reconcile with the principles of proportionality and human dignity, as well as with the duty to prevent serious harm.

For that reason, the possible disclosure of information to authorities should be subject to case-by-case assessment, considering, in particular:

- the seriousness of the facts;
- the current nature of the risk;
- the imminence of the danger;
- the need for intervention;
- the possibility of limited and strictly proportionate disclosures.

Accordingly, an interpretation leading to an absolute prohibition on the disclosure of information does not appear to adequately reflect the complexity of the concrete situations described above, nor the necessary balancing of interests and assessment of proportionality advocated by European guidance on scientific research.

7. Need to clarify the reverse scenario

Example 17 presupposes that participants are potential victims and that researchers collect data about perpetrators. The Guidelines should also clarify how the reverse situation should be analysed, namely where research participants are alleged or self-disclosed perpetrators and provide information about identifiable victims, whether adults or children, including accounts of physical, emotional, or sexual violence.

In such a scenario, it should not be assumed, without further assessment, that the same conclusions necessarily apply as regards secrecy and non-disclosure to third parties. On the contrary, the analysis should expressly consider the legal and ethical obligations to protect vulnerable persons and to communicate situations involving current risk, serious danger, or ongoing harm, particularly where children or other persons in situations of vulnerability may be affected.

This reverse scenario further illustrates why Example 17 should not be read as establishing an absolute rule of non-disclosure to competent authorities. Rather, the Guidelines should make clear that confidentiality and statutory secrecy must be reconciled with proportionate, legally grounded, and ethically justified mechanisms for managing serious risks and protecting identifiable third parties.

III. Conclusion

CEIC-UA recognizes the relevance of protecting duties of secrecy and confidentiality and safeguarding research participants, as well as the legitimacy of applying the exception provided for in Article 14(5)(d) GDPR.

However, the wording of Example 17 adopts an excessively rigid approach to the duty of secrecy, particularly by suggesting an almost complete impossibility of disclosure to competent authorities without adequate ethical, legal, and factual contextualization.

For all the reasons set out above, and particularly having regard to the European ethical guidance referred to above, the Guidelines should clarify that duties of secrecy and confidentiality are not capable of automatic application, but instead require an assessment based on proportionality, the seriousness of the situation, and the effective protection of participants. It is further suggested that this point be reformulated to clearly distinguish the exemption from the duty to provide information under Article 14 GDPR from any disclosure of information to competent authorities, which should be limited to what is strictly necessary.

References

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