

25.6.2026

Statement on the Public Consultation: Guidelines 1/2026 on the processing of personal data for scientific research purposes

The University of Eastern Finland welcomes the opportunity to provide its views on the draft Guidelines 1/2026 on the processing of personal data for scientific research purposes.

General comments

The University of Eastern Finland welcomes the Guidelines and considers that they provide valuable clarifications and guidance on the processing of personal data for scientific research purposes.

The Guidelines appropriately acknowledge that complementing legislation at Union and Member State level is both necessary and permissible. Consequently, matters falling within national competence are not addressed in detail, which is understandable.

Freedom of research is guaranteed under Article 13 of the Charter of Fundamental Rights of the European Union and, in Finland, inter alia under the Constitution and the Universities Act. As a fundamental right, it confers on researchers a degree of academic freedom and an autonomous position in handling research data, even where they are employed by a research organisation. Traditionally, this autonomy has also entailed the researcher's personal responsibility for the personal data being processed. Scientific research purposes are recognised in the GDPR as a special category of processing, as reflected in Article 89, which permits certain derogations, including in relation to data subject rights. In the view of the University of Eastern Finland, the Guidelines do not fully achieve an appropriate balance between data protection requirements and the freedom of research and the autonomous role of researchers.

Scope of the concept of scientific research

The University considers it particularly helpful that the Guidelines clarify when the processing of personal data constitutes scientific research. This clarification is essential for determining the

25.6.2026

applicable legal basis. The University of Eastern Finland, however, emphasizes that a European Union institution does not have the competence to define what constitutes scientific research. From the perspective of Finnish national legislation, any restrictions on the freedom of research must be laid down precisely and narrowly in law. Such restrictions cannot be based on guidance. For this reason, this guidance should emphasize that the principles are general guidelines and are not intended to steer the content or methods of conducting scientific research. In Finland, the conduct of scientific research is additionally guided by self-regulation within the respective field.

However, the University would have welcomed more guidance on the open sharing of research data. In the context of open science, publishers increasingly require that underlying research data be made available on an open access basis alongside publications. In practice, researchers often cannot comply with such requirements where datasets contain personal data, even if strongly pseudonymised. Further clarification is needed of the conditions under which research data may be shared with other researchers.

Data protection principles

Purpose limitation

The University welcomes the clear recognition that further processing of personal data for scientific research purposes is, in principle, compatible with the original purpose, in accordance with the GDPR.

It is also appropriate that the Guidelines recognise that a change of legal basis is not always required when personal data collected for one purpose is later used for scientific research. Nevertheless, it should be acknowledged that certain legal bases, such as contractual necessity or legal obligation, may not be suitable for scientific research in all national contexts, including Finland.

Storage limitation

Under the Finnish Universities Act, the mission of universities is to promote free research. On that basis, they should be entitled to retain research data for future research, even where future projects cannot be specified in detail. The University therefore welcomes the positive approach taken in the Guidelines towards the storage of research data and the absence of a requirement to delete data immediately after the completion of a study.

The University, however, emphasizes that the preservation of research data and the responsibilities related to it require national regulation, as EU regulation does not contain specific provisions on this

25.6.2026

matter. The processing and transfer of data belonging to special categories of personal data or other sensitive data, for example to a research institution for storage, must be regulated in national legislation. However, in Finland, there is currently no such regulation.

Lawfulness

The University welcomes the identification of the legal bases under Article 6 of the GDPR that may be relevant for scientific research, namely consent, legal obligation, public interest, and legitimate interest.

However, the University considers that the Guidelines place disproportionate emphasis on consent as a legal basis. While consent is addressed extensively, other legal bases receive comparatively limited attention. The use of public interest is left largely to national discretion, which explains its limited treatment. In Finland, scientific research is extensively based on the legal basis of public interest, as provided for in the national Data Protection Act (Section 4(1)).

The University considers that consent is generally not very well suited as a legal basis for scientific research conducted in universities. The voluntariness of consent may be questionable where a clear imbalance exists between the data subject and the controller. Consent-based processing of personal data is possible when the data is collected directly from the data subjects. However, in situations where research is based on data stored in repositories and originally collected for other purposes, it is necessary to rely on public interest as the legal basis for processing. Typically, the datasets collected are very extensive, making it impossible to obtain consent from data subjects for the purposes of scientific research.

The distinction made in the Guidelines between consent to participate in research and consent to the processing of personal data is welcomed. It is important to clarify that consent as a legal basis requires a specific consent to processing, not merely consent to participation.

In Finland, a widely applied model combines the use of public interest as the legal basis with the collection of ethical consent to participate. This approach ensures that participation is based on informed consent in accordance with research ethics, while allowing processing to rely on a legal basis other than consent. The University encourages the Guidelines to explicitly recognise this model.

The University also welcomes the acknowledgment of broad consent for certain fields of scientific research. It would be desirable to clarify that ethical consent to participate may also be sought in a broad manner, while relying on public interest as the legal basis and ensuring appropriate transparency towards data subjects.

25.6.2026

The University welcomes the clarification that public interest may serve as a legal basis not only for public authorities but also for private entities conducting scientific research.

Transparency obligations

With regard to transparency obligations, the University emphasises the importance of the data minimisation principle under Article 5 of the GDPR and the relevance of Article 11. Where the purposes of processing do not require the retention of direct identifiers, such identifiers should not be kept solely to facilitate the exercise of data subject rights.

In this respect, the University considers that an approach requiring the retention of identifiers and contact details for transparency purposes, even where not required for research purposes, would be at odds with the principle of data minimisation. As a general rule, research data should be pseudonymised or anonymised as soon as direct identifiers are no longer necessary.

Practical considerations should also be taken into account. In long-term studies, such as cohort studies, contact details may change over time, and maintaining up-to-date information may impose a disproportionate burden on researchers. In such cases, providing information through publicly accessible means, such as project websites, is often a pragmatic solution.

In Finland, a significant amount of research is conducted using register-based data, particularly in the health sector. Such data are typically provided in a strongly pseudonymised form, rendering identification without additional information being impossible. In this context, and in light of forthcoming EU legislation such as the European Health Data Space, individual information may in practice be impossible in research based on register data.

The University therefore considers it essential that the derogation under Article 14(5)(b) of the GDPR remains available where providing information is impossible or would involve disproportionate effort, provided that appropriate safeguards under Article 89 are implemented. This derogation should not be interpreted restrictively.

Allocation of roles and responsibilities

The Guidelines include a description of the characteristics of a controller, a processor, and joint controllers. The description of these characteristics and the interpretation of paragraph 137 regarding the controllership of a research organisation are, from the perspective of the university's operations, somewhat contradictory.

25.6.2026

In Finland, under the Universities Act, the mission of universities is to promote free research, and the university, as an employer, cannot act in a way that would jeopardise academic freedom. Researchers at universities are therefore, in a certain sense, in an autonomous position compared to, for example, other staff. In Finland, academic freedom is associated with a strong personal responsibility of the researcher for the personal data they process. An individual researcher or a research group often independently determines the research questions and research methods. Accordingly, based on the criteria for a controller, the role of controller may fall on an individual researcher or jointly on members of a research group. However, research is conducted in the name of the university, using the university's technical tools and storage platforms and in accordance with the university's guidelines. Nevertheless, in such cases the university does not act in a role that would meet the definition of a controller. According to the case law of the Court of Justice of the European Union (29 July 2019, *Fashion ID*, C-40/17, EU:C:2019:629, paragraph 74; *Nacionalinis visuomenės sveikatos centras prie Sveikatos apsaugos ministerijos*, C-683/21, paragraph 41), each controller must independently meet the definition of a controller as set out in Article 4(7) of the GDPR. Based on this case law, the guidance at issue cannot make generalisations as to who acts as a controller in scientific research; this must be assessed on a case-by-case basis. A Union institution does not have the competence to issue generalised guidance on who acts as a controller in scientific research.

In Finland, research conducted at universities is divided into so-called contract research funded by external (supplementary) funding and so-called free research. In addition, there are also researchers at universities who conduct research on personal grants and who are not always employed by the university.

In externally funded contract research, the rights (including ownership) and control over the research results rest with the university, and the university also participates in drafting the research protocol. In such cases, the university can be considered to act as the controller.

By contrast, in so-called free research and personal grant-funded research, the rights, ownership, and control over the research results rest with the researcher. Some grant-funded researchers are not in an employment relationship with the university. Researchers also independently define the research questions and prepare the research plan, in which case, according to the criteria for a controller, the researchers themselves should be considered controllers.

Degree students and doctoral researchers at universities often process personal data when preparing their theses. Students completing bachelor's and master's theses do not carry out their work in an employment relationship with the university. Some doctoral researchers are employed by the university, while others are not. A thesis may be published as part of the results of a broader research project led by the university, in which case the university is the controller of data. However,

25.6.2026

a large proportion of theses are such that the student has defined the research questions, prepared the research protocol, collected the source data for themselves, and owns it, and the university does not exercise actual control over the processing of personal data, even though supervisors appointed by the university guide the work.

The University of Eastern Finland considers that the university cannot act as a controller for research data where it has not determined the purposes or means of processing. The university notes that, in the absence of EU-level legislation, there is a need to further clarify the role of universities in the governance of research data in national legislation.

Joint controllership

The University notes that Article 26 of the GDPR does not require a formal contract for joint controllership, but rather an arrangement in a transparent manner. While a contractual agreement may be appropriate in certain cases, in other situations transparency can be ensured through documented arrangements, such as privacy notices. The Guidelines should reflect this flexibility.

The University refers in this respect to the case law of the Court of Justice of the European Union (C-683/21, paragraph 45), according to which the existence of such an arrangement is not a precondition for two or more entities to be characterised as joint controllers; rather, it is an obligation imposed on joint controllers under Article 26(1) once they have been designated as such, in order to ensure compliance with the obligations binding them under the GDPR.

Safeguards

The University welcomes the comprehensive treatment of safeguards. However, it would be beneficial to clarify that anonymised data cannot be used without limitation for any purpose, despite falling outside the scope of the GDPR. Furthermore, the anonymisation process itself constitutes processing of personal data and should be clearly recognised as such.

Conclusion

The University of Eastern Finland appreciates the efforts of the European Data Protection Board in providing guidance on the processing of personal data for scientific research purposes. The University encourages further clarification in the areas highlighted above, in particular with regard to

25.6.2026

the role of public interest as a legal basis, the practical implementation of transparency obligations, and the specific characteristics of the research environment.

This statement has been approved by Jussi Pihlajamäki, Vice Rector responsible for research at the University of Eastern Finland, and the following members of the University of Eastern Finland staff have participated in its preparation and commenting (in alphabetical order):

Helena Eronen, Data Protection Officer, General Administration and Legal Affairs, University Services
Anu Liikanen, Director of Research and Innovation Services, Research and Innovation Services, University Services
Petri Rintamäki, Chief Legal Officer, General Administration and Legal Affairs, University Services
Tomi Voutilainen, Professor of Public Law, Law School, Faculty of Social Sciences and Business Studies