Gesundheit Österreich GmbH

Comments by Gesundheit Österreich GmbH on EDPB Guidelines 1/2026

Gesundheit Österreich GmbH (GÖG) is the Austrian National Public Health Institute, responsible for researching and planning public healthcare in Austria, and also acts as the national competence and funding centre for the promotion of health.

GÖG welcomes the opportunity to comment on the EDPB Guidelines 1/2026 on processing of personal data for scientific research purposes.

GÖG generally supports the objective of the Guidelines. The processing of personal data, including health data, is indispensable for public health research, health services research, health reporting, health system planning, evaluation, quality assurance and evidence-informed policy-making. In this regard, the Guidelines provide a valuable contribution to legal certainty by clarifying the application of the GDPR to scientific research and by acknowledging the societal value of research carried out in the public interest.

GÖG particularly welcomes the recognition that the concept of scientific research must be interpreted broadly, while being limited to genuinely scientific activities. The key-indicative factors proposed by the EDPB are, in principle, helpful. However, GÖG considers it important that the final Guidelines make clear that scientific research in the meaning of the GDPR is not limited to academic or peer-reviewed-publication-oriented research. Applied public health research, statutory health reporting, health system monitoring, register-based research, evaluation studies, quality assurance and evidence-informed policy-making support should also be covered, provided that they are carried out according to recognised methodological and ethical standards.

GÖG also welcomes the clarification that further processing of personal data for scientific research purposes benefits from the presumption of compatibility under Article 5(1)(b) GDPR. This is of particular importance for health data infrastructures, registries, longitudinal datasets and secondary use of routinely collected health data. Such forms of processing are essential for identifying health trends, assessing the quality and efficiency of health services, evaluating public health measures and supporting evidence-informed decision-making.

At the same time, GÖG stresses that the presumption of compatibility must be accompanied by clear, risk-based safeguards. In the health sector, this includes robust governance structures, access controls, pseudonymisation or anonymisation where appropriate, secure processing environments, confidentiality obligations, transparency measures and clear rules on further use. These safeguards should be designed in a way that protects the rights and freedoms of data subjects without unnecessarily restricting research carried out in the public interest.

With regard to legal bases, GÖG welcomes the emphasis on Article 6(1)(e) GDPR for research carried out in the public interest or in the exercise of official authority. For statutory public health tasks and health system-related research, consent will often not be the most appropriate legal basis. In many cases, reliance on consent may lead to selection bias, unequal representation, practical infeasibility or uncertainty

regarding the voluntariness of consent. The final Guidelines should therefore underline that, where Union or Member State law provides a sufficient legal basis and appropriate safeguards, public-interest processing may be more suitable than consent for certain forms of public health research and secondary use of health data.

GÖG further welcomes the discussion of broad consent and dynamic consent. These concepts can be useful in certain research contexts, especially where future research questions cannot be fully specified at the time of data collection. However, the Guidelines should avoid creating the impression that consent is the default solution for health-related research. In particular, large-scale register-based research, statutory reporting and public health monitoring often require legal bases other than consent in order to ensure completeness, representativeness and reliability of results.

GÖG also supports the strong emphasis on transparency. Transparency is essential for public trust in the use of health data. However, transparency obligations should be interpreted and applied in a proportionate and risk-based manner, especially where large-scale, pseudonymised or register-based datasets are processed and where direct contact with data subjects is not possible or would require the retention or re-establishment of identifying information. In such cases, public information portals, layered transparency notices, governance documentation, access policies and general communication measures may be more appropriate than individual notification.

The final Guidelines should also further clarify the allocation of responsibilities between controllers, joint controllers and processors in complex research environments. Health data research frequently involves public bodies, research institutions, register operators, data access bodies, technical service providers and private partners. A clear and practicable distinction between separate controllership, joint controllership and processing on behalf of a controller is essential to ensure accountability and effective exercise of data subject rights.

Finally, GÖG welcomes the emphasis on appropriate safeguards under Article 89(1) GDPR, including anonymisation, pseudonymisation, secure processing environments, ethical oversight, privacy-enhancing technologies and confidentiality arrangements. The final Guidelines should confirm that safeguards should be proportionate to the risks, the nature of the data, the research context and the public-interest value of the processing. In particular, the use of directly identifying data should be limited to cases where it is necessary and proportionate, while pseudonymised or anonymised data should be used wherever the research purpose can be achieved in that manner.

In conclusion, GÖG supports the overall direction of the Guidelines and considers them an important step towards greater legal certainty for scientific research. At the same time, GÖG recommends that the final Guidelines provide further clarification for applied public health research, statutory health reporting, register-based research, health data infrastructures, secondary use of health data, transparency in pseudonymised data environments and the allocation of responsibilities in complex research settings. Such clarifications would help ensure an appropriate balance between the protection of personal data and the societal need for high-quality, evidence-informed public health research.