

Subject: Feedback on Guidelines 1/2026 on Processing of Personal Data for Scientific Research Purposes

I welcome the EDPB's comprehensive Guidelines 1/2026 and strongly support the emphasis on methodical research, ethical standards, verifiability, transparency, and appropriate safeguards, as outlined in the Executive Summary and Section 2.1 of the document. These principles are essential for ensuring that scientific research using personal data remains both responsible and robust.

In my work with large-scale health datasets and AI-based analytical methods, I have observed that the *meaning* of standardized clinical codes and data elements can shift over time due to changes in workflows, devices, care settings, and population behavior. These “semantic drift” effects occur even when the underlying code remains unchanged. For example, a LOINC code for a vital sign may represent a nurse-measured clinical value in one period and a patient-generated home-device measurement in a later period. Such shifts can affect reproducibility, comparability, and the scientific validity of long-term or secondary-use datasets.

Given the Guidelines' focus on verifiability (Section 2.1(iii)), transparency (Section 5), and safeguards for long-term processing (Section 3.2 and Section 8), I encourage the EDPB to consider acknowledging semantic drift as a methodological risk in scientific research using personal data. Even a brief reference would help controllers and researchers recognize that meaning-level changes in data can influence scientific outcomes.

To support the objectives of Article 89(1) GDPR, the following lightweight safeguards may be helpful for long-running research infrastructures:

1. Periodic assessment of meaning stability in key data elements,
2. Documentation of workflow or device changes that affect interpretation, and
3. Transparency about temporal context when reusing historical health data.

These additions would strengthen the Guidelines' focus on scientific integrity, improve the reliability of secondary-use health data, and support responsible AI development in clinical and public-health research.

Thank you for the opportunity to contribute to this important consultation.