

Consultation Response to the European Data Protection Board (EDPB)

The NTNU University Library coordinates guidance and support for personal data in research at NTNU. We are pleased that the EDPB have issued guidelines on the processing of personal data for scientific research purposes but note that there are some issues that could still benefit from further clarification.

The following comments are made by Research Data @NTNU, NTNU's central support service for research data management, which is coordinated by the University Library.

Open Science

The European research ecosystem places Open Science at the core of its agenda. The EU's own strategies (e.g., European Open Science Cloud, Horizon Europe) explicitly promote open data and broad data sharing to accelerate discovery and societal benefit.

It is therefore surprising that the current EDPB guidance makes no explicit reference to "open science" or "open data" despite these policy priorities. This omission hampers the ability of researchers to navigate GDPR-compliance with the EU's open-science objectives and will contribute to confusion regarding what data could be shared and with whom.

The Open Science mantra, "as open as possible, as closed as necessary", is of little practical use for researchers who struggle to determine whether their data could be shared or not. We therefore suggest that the EDPB introduce a section that discusses how open data can be balanced with GDPR-compliance and that specifies how the rights of the data subjects could be safeguarded while still being "as open as possible". A list of elements that must be included in the information to the research participants (data subjects) would be helpful in this regard.

Legal bases and the rights of data subjects

Furthermore, we would appreciate a clarification of data-subject rights under different legal bases. In general, there is often a stronger protection of rights if consent is used as the basis for processing. However, quite a few exceptions have been included in the GDPR (and recitals) for scientific research purposes is scientific research. It is unclear whether there should be a higher threshold for using the exceptions when consent is used as the basis for processing or whether the same considerations (such as public interest and legitimate interest) could be applied because the purpose is research.

Broad consent

EDPB emphasizes in these guidelines that broad consent is a valid exception according to Recital 33 if the purpose is scientific research. However, the recommended use of

dynamic consent (re-consenting when specific details become known) underestimates that requiring a fresh “dynamic” consent from each research participants for every new use often is impossible in practice. For many research purposes, including verification of results by the scientific community, not retrieving new consent from every single data subject would jeopardise the scientific value of the data.

Necessary vs strictly necessary

The draft frequently replaces the GDPR term “necessary” with “strictly necessary”, thereby imposing a very high threshold for invoking research exemptions. This practice creates legal uncertainty as regulators and institutions may interpret the requirement as prohibitive. Furthermore, it contradicts the GDPR’s own wording, which deliberately uses “necessary” to allow a proportionate balancing of interests.

We request that the EDPB align its terminology with the GDPR text, using “necessary” where the regulation says so and where stricter safeguards are advisable (e.g., for highly sensitive health data), provide explicit, optional safeguards rather than redefining the baseline standard as set by GDPR and its recitals.

Data protection impact assessments (DPIA)

The guidelines should provide dedicated examples of research projects where conducting a DPIA would be required and where it would not be required. In particular, it should give more clarity to what would constitute large scale data collection in a research setting.