Europe's New Rules on Research Data Are the Best We've Had. That's Part of the Problem.

What EDPB Guidelines 1/2026 still needs to fix before it shapes a decade of scientific research policy.

Eight years is a long time to wait for clarity. Since the GDPR came into force in 2018, researchers, NGOs and data protection officers across Europe have been working with provisional guidance, supervisory authority opinions that contradict each other across Member States, and a pervasive sense that nobody quite agrees on what "scientific research" actually means for the purposes of data law.

On 15 April 2026, the European Data Protection Board (EDPB) published Guidelines 1/2026 on the processing of personal data for scientific research purposes. The public consultation runs until 25 June 2026. At 67 pages and 171 paragraphs, this is the most substantial EU-wide interpretation of the GDPR's research provisions since the Regulation was adopted. In several important respects, it is genuinely good.

And yet. If you work in a health-policy NGO, run a citizen science project on air quality, or manage research operations with a team of four people and a shared laptop, the Guidelines may leave you wondering whether they were written with you in mind at all.

What the Guidelines Actually Resolve

It is worth spending a moment on what the document achieves, because the gaps only make sense against that backdrop.

The EDPB has finally put in writing that further processing of personal data for scientific research is *presumed compatible* with the original collection purpose under Article 5(1)(b). This removes the need for a compatibility assessment under Article 6(4) when repurposing data for research, which was an ongoing source of confusion. The Board has also confirmed that both broad consent (covering a defined area of research, rather than a specific project) and dynamic consent (securing permissions progressively as project stages crystallise) are valid under the GDPR. Biobanks, longitudinal health studies and federated databases have been waiting for that signal for years.

The document also works through controller, processor and joint-controller questions in research contexts with a level of specificity that has been absent until now. It confirms that a pharmaceutical sponsor who drafts a clinical trial protocol is a controller even if they never handle directly identifiable data. It clarifies that Contract Research Organisations executing instructions under an Article 28 agreement are processors, not controllers. These are not trivial clarifications. They affect how research consortia structure their contracts and who is liable when things go wrong.

So the foundation is there. The problem is what has been left out.

The AI Blind Spot

The EDPB opens its executive summary by acknowledging that recent advances in artificial intelligence "enable researchers to use and analyse data in ways that were not possible only a couple of years ago." That framing implies the Guidelines will address AI as a research instrument.

They do not. Not once.

Example 2 in the Guidelines features a startup researching bias in generative AI models. AI is the *subject* of the research. But there is no guidance anywhere in the document for the far more common situation: an NGO health researcher feeding interview transcripts into Claude or ChatGPT to assist with thematic coding, a university team using Gemini to summarise survey responses, or a public health team running a dataset through an API to generate preliminary analysis.

This matters for two reasons. First, every time personal data goes into a third-country AI model, a Chapter V international data transfer is triggered. The Guidelines mention international transfers in one footnote (footnote 85, a US Cloud Act reference) and a single paragraph about transparency obligations. There is no guidance on how research controllers should document or manage transfers to AI providers in the United States. That is a significant omission in a document meant to govern research practice for the next decade.

Second, the question of whether an AI provider is a processor, a joint controller, or an independent controller changes everything about how a research organisation must structure its relationships. The Guidelines give only the generic functional test from Section 7. The closest the document comes to addressing the issue is paragraph 132, which notes that "the choice of software to be used" is a non-essential means that may be left to a processor. That reasoning might hold if AI providers simply execute instructions. It does not hold if they also use inputs to

improve their models. The Bavarian State Commissioner for Data Protection analysed this in March 2025 and concluded that training-on-inputs behaviour pushes a provider from processor to independent controller. The Guidelines say nothing on this.

The consultation window, which closes on 25 June 2026, is the moment to raise these points formally.

The Credentialing Gap That Excludes the People Who Need This Most

Factor iv of the six-factor test for scientific research requires that researchers processing personal data hold "academic (e.g. a PhD title) or scientific qualifications (e.g. proven experience or recognition) in the relevant field of research."

The six-factor test is designed to stop commercial marketing analytics from dressing itself up as research to claim GDPR exemptions. That is a reasonable objective. But the way the test is written creates a serious problem for citizen science.

Europe's Open Science agenda, which the EU has been funding and promoting since at least 2016, depends substantially on community-led research. The WeObserve project, a three-year European-funded initiative, built a network of citizen observatories across the continent where local volunteers, environmental activists and community members gather environmental data without academic titles. Under the current draft of Factor iv, it is not clear that any of them qualify as "researchers" for GDPR purposes.

This is not a corner case. It affects biodiversity monitoring, localised air and water quality tracking, epidemiological community surveillance, and dozens of other areas where citizen participation is how the data gets collected at all. If these initiatives cannot rely on the scientific research provisions of the GDPR, they face the full compliance burden of standard data processing rules. That burden is designed for organisations with legal departments and IT teams, not for a community group tracking particulate matter near a motorway.

The fix here is straightforward. Factor iv should be revised to make clear that lay or volunteer researchers satisfy the autonomy and independence requirement when they operate under the governance of an established citizen science institution, an academic partner, or a recognised open-science framework. The absence of a PhD should not, by itself, disqualify a research activity that meets every other factor in the test.

The Compliance Gap for Small Organisations

Nothing in Guidelines 1/2026 distinguishes between a university hospital network running a multi-year genomics study and a five-person health-policy NGO producing a report on patient access to medication in three Member States.

The Article 89(1) safeguard catalogue lists independent ethical oversight bodies, secure processing environments, privacy-enhancing technologies, pseudonymisation infrastructure, regular re-verification of anonymisation effectiveness, and consent management platforms. These are reasonable expectations for a well-resourced research institution. For a small NGO, several of them are not achievable without significant external support.

The EU Agency for Fundamental Rights found in 2019 that 77% of civil society organisations reported challenges in implementing the GDPR. The document they were struggling with at the time was far less demanding than the safeguard package outlined in Guidelines 1/2026.

The GDPR's own risk-based architecture is meant to scale obligations to risk. Articles 40 and 42 specifically instruct that "the specific needs of micro, small and medium-sized enterprises" should be taken into account when developing codes of conduct and certification schemes. The Guidelines acknowledge none of this in operational terms. They treat non-profit and commercial research organisations identically, which means that the practical compliance bar for a small NGO is set at the level of a pharmaceutical company conducting international clinical trials.

The most workable solution here would be a sector code of conduct under Article 40 GDPR, developed for civil society research organisations, monitored by an accredited body, and pre-specifying proportionate safeguards and approved AI-tool configurations. This would give small organisations a compliance template rather than requiring each of them to reinvent the wheel individually. It would also allow supervisory authorities to focus enforcement on genuine risk rather than on whether an under-resourced advocacy organisation has a dedicated pseudonymisation officer.

What the UK Has Done Differently

It is instructive to compare the EDPB's approach with what the UK legislature chose in the Data (Use and Access) Act 2025.

The UK definition of scientific research in that Act reads: "any research that can reasonably be described as scientific, whether publicly or privately funded and whether carried out as a commercial or non-commercial activity." The Information Commissioner's Office followed up with a Research, Archiving and Statistics guidance consultation in February 2026.

This is a meaningfully broader and more accessible standard than the EDPB's six-factor test. It would accommodate citizen science. It would accommodate NGO policy research. It would accommodate a small organisation without a formal ethical review board, provided the processing was genuinely research-oriented and proportionate.

Post-Brexit comparisons are complicated, and the UK's approach carries its own risks if it becomes a haven for data processing that would not survive GDPR scrutiny. But the contrast illustrates that a functional definition of scientific research does not have to be this demanding to achieve the underlying goal of excluding commercial analytics dressed up as research.

The Missing Mechanism: No Way to Get It Right Before You Start

One structural problem in the Guidelines deserves more attention than it has received. There is no ex-ante pre-clearance mechanism.

Under the current framework, a research organisation that wants to know whether its processing qualifies as scientific research under the GDPR must conduct its own self-assessment, document it in a DPIA or research protocol, and proceed at its own legal risk. If a supervisory authority subsequently decides during an audit that the activity does not meet the six-factor test, the organisation faces retroactive enforcement, potential fines under Article 83, and processing bans that could destroy years of research.

This is a particular problem for NGOs that are already operating close to the boundary between advocacy and research, and for organisations using AI tools that have not yet been clearly categorised by any supervisory authority.

The EDPB should use the certification mechanism in Article 42 to establish a voluntary "Research Data Protection Seal" framework. Research consortia, clinical sponsors and NGOs would be able to submit their research protocols, broad consent templates and pseudonymisation approaches to an accredited certification body for review before they begin processing. A valid seal would create a rebuttable presumption of compliance and shield the research from retroactive enforcement. It would not prevent regulators from investigating serious breaches. But it would give organisations that are genuinely trying to get it right some protection for having tried.

What Should Happen Before June 2026

The consultation window closes on 25 June 2026. The EDPB will revise the text before final

adoption, and formal responses from stakeholders genuinely shape those revisions.

Civil society organisations, research institutions and data protection practitioners who work with the communities these Guidelines affect should submit responses that specifically address: the treatment of citizen science and NGO advocacy research under Factor iv; the absence of any guidance on AI tools as research instruments; the need for Chapter V transfer guidance in the context of third-country AI providers; and the absence of proportionality provisions for small and under-resourced organisations.

The Guidelines are the best framework Europe has had for research data protection. The consultation is the opportunity to make them adequate for the research landscape that actually exists, rather than the one that existed when the GDPR was written.

This article draws on EDPB Guidelines 1/2026 (adopted 15 April 2026), EDPB Opinion 28/2024 on AI models, the UK Data (Use and Access) Act 2025, and analysis from Ropes & Gray, Hogan Lovells, Goodwin Law and the EU Agency for Fundamental Rights. It is not legal advice.