A response to the EDPB's Guidelines 1/2026 on processing of personal data for scientific research purposes

This paper is submitted on behalf of:

EFAMRO the European Federation of Associations of Market Research Organisations. Founded in 1992, EFAMRO represents the interests of market, opinion and social research in Europe. Its members are national trade associations for research businesses across Europe.

Esomar the worldwide, not-for-profit membership organisation committed to empowering and connecting the research, insights, and analytics community. Since 1947, we have empowered professionals and businesses to unlock their potential on both the global and local stage, fostering connections, collaboration, growth, and knowledge. Today, we represent and provide connections among 50,000+ individuals and 750+ companies in 130+ countries.

EFAMRO and Esomar represent the research and insights sector, accounting for a reported annual turnover of €34.02 billion in Europe.

1 About Market, Opinion and Social Research

1.1. Market research is comprised of all forms of market, opinion, and social research.

1.2. Market, opinion and social research is the systematic gathering, analysis and interpretation of information about individuals or organisations. It uses the statistical and/or analytical methods and techniques of the applied social, behavioural, data and other sciences to generate insight and support decision making by the general public, governments, providers of goods and services, and non-profit organisations.

1.3. Market, opinion and social research stand at the heart of well-informed social, political and commercial decisions. Its purpose is to deliver information and insights about people's behaviour, needs and attitudes to inform decision making by providers of goods and services, governments, individuals, and society at large. Insight into what makes the success of a product, business initiative or government policy strategy is often the hidden – yet defining – factor that determines success and failure. It is our sector that provides the deeper intelligence needed for our world today by representing citizens' authentic voices, from all levels of society, in an unbiased and representative way by applying the tenets of statistical and scientific methods.

1.4. Market, opinion and social research associations apply a comprehensive framework for self-regulation to ensure that researchers meet their ethical, professional, and legal responsibilities to the individuals whose data they use in

research and to the clients and organisations which commission research. Members subscribe to self-regulation schemes that protect participants' rights. These are built on established international standards set forth by the International Chamber of Commerce/Esomar International Code and the national codes across many EU countries[1].

2 Purpose of Response

2.1 EFAMRO and Esomar welcome the EDPB's efforts to clarify the processing of personal data for scientific research purposes, and to provide guidance on key GDPR issues, including lawfulness, compatibility, transparency, data subject rights derogations, roles, and safeguards. However, we are concerned that the Guidelines do not fully give effect to the GDPR's total conception of scientific research. In particular, while the Guidelines expressly recognise that scientific research may be conducted on a commercial basis, including relying on legitimate interests, this recognition is not consistently operationalised throughout the document or reflected in the accompanying examples.

2.2 This is difficult to reconcile with Article 89 GDPR and Recital 159, which make clear that "scientific research" should be interpreted broadly, including research carried out in privately funded and commercial contexts. That understanding is also consistent with internationally recognised frameworks such as the Frascati Manual[2], which recognises scientific research across both public and private sectors. As drafted, the Guidelines risk creating further uncertainty for organisations conducting legitimate scientific research outside of academic or medical contexts, despite such activities falling within the scope envisaged by the GDPR itself.

2.3 We urge the EDPB to also rebalance the examples and explanatory analysis with the Guidelines to demonstrate more clearly how commercial research organisations can satisfy the relevant criteria where the activity is genuinely scientific in nature. At present, many of the examples appear weighted toward academic, public sector, or clinical research environments, which risks narrowing and confining the use and application of scientific research provisions, or implying that they are more relevant or exclusive to these types of research models.

2.4 To improve legal certainty and practical usability, the Guidelines should therefore include additional examples illustrating scientific research conducted in commercial settings that nonetheless satisfies the relevant safeguards and methodological standards under Article 89 GDPR. This could include, for example, pharmaceutical market research or longitudinal research projects involving repeated data collection over time to analyse behavioural, social, economic, or public policy trends; "blind" or double-blind studies designed to reduce bias and preserve methodological integrity; large-scale observational research; and research

[1] ICC/Esomar International Code on Market, Opinion and Social Research and Data Analytics: https://esomar.org/code-and-guidelines/icc-esomar-code

[2] https://www.oecd.org/en/publications/2015/10/frascati-manual-2015_g1g57dcb.html

undertaken by independent market, social, and opinion research organisations using recognised scientific methods to generate generalisable insights.

2.5 Including such examples would better reflect the broad interpretation of "scientific research" envisaged by Recital 159 GDPR and would help ensure that the Guidelines provide workable and technologically neutral guidance across the full spectrum of legitimate scientific research activities, including those conducted outside academic or medical contexts.

2.6 To assist the EDPB in this regard, EFAMRO and Esomar have included, in the Annex to this submission, several practical examples illustrating market, opinion and social research activities that satisfy the 'key indicative factors' of scientific research identified in the Guidelines. These examples demonstrate how scientific research can be conducted in commercial and privately funded environments while adhering to recognised scientific methodologies, ethical standards, appropriate governance arrangements, and the safeguards required under the GDPR. We hope they will assist the EDPB in ensuring that the final Guidelines reflect the full range of legitimate scientific research activities envisaged by Recital 159 GDPR.

3 Restrictive Application of the Indicative Factors

3.1 We recognise and support the EDPB's intention to identify common characteristics that may assist in determining whether an activity constitutes "scientific research" under the GDPR. It is worth noting that the market, opinion and social research is fully capable of satisfying the key indicative factors identified in the Guidelines and should be expressly recognised as capable of constituting scientific research. However, we are concerned that the current drafting risks creating an interpretation that is unduly narrow in practice, particularly for privately funded, commercially commissioned, applied, market, opinion and social research.

3.2 Although Clause 11 states that the criteria are "indicative", the language, and examples throughout the Guidelines risk creating the impression that organisations are expected to satisfy all of the factors in order to qualify as scientific research. In particular, the Guidelines appear to require organisations to justify or explain the absence of certain criterion, which may in practice cause the criteria to operate as quasi-mandatory conditions rather than contextual indicators.

3.3 In effect, the Guidelines do not sufficiently emphasise that:
- no individual factor is mandatory;
- not all factors will be present in every legitimate form of scientific research, and;
- the absence of a particular factor should not create a presumption against qualification as scientific research.

3.4 Without stronger clarification, there is a material risk that supervisory authorities and organisations will apply the criteria conservatively, leading to the exclusion of legitimate forms of scientific research that do not align closely with academic, university, or medical research models.

3.5 This would be inconsistent with Recital 159 GDPR, which expressly requires the notion of scientific research to be interpreted "in a broad manner", including research conducted in privately funded and applied contexts.

3.6 In relation to the objectives of research, we recommend that the Guidelines avoid requiring research to contribute simultaneously to both knowledge and wellbeing. Market, opinion and social research may contribute directly to the growth of knowledge, improved evidence-based decision making, public understanding, or social and economic insight, even where the link to individual or collective wellbeing is indirect or dependent on the topic being studied. We therefore recommend replacing references to "knowledge and wellbeing" with "knowledge and/or wellbeing", to reflect the broad range of legitimate scientific research purposes recognised by Recital 159 GDPR.

3.7 We would also welcome clarification of the reference to applying existing knowledge in "novel ways". As currently drafted, it is unclear what level of novelty is required, or how this criterion should be assessed in applied, commercial, market, opinion and social research contexts. Many research projects apply established and new scientific methods to new populations, markets, behaviours, policy questions, datasets, or decision-making contexts. The Guidelines should clarify that such applications may satisfy this factor where they generate new insights or support the development, testing or application of knowledge in a different context.

4 Methodological and Systematic Approach

4.1 A methodological and systematic approach is fundamental to the sector. Research activities are commonly based on established scientific disciplines including statistics, sociology, behavioural science, psychology, economics, and data science.

4.2 The sector routinely employs recognised scientific methodologies, including:

- longitudinal studies;
- observational research;
- structured sampling methodologies;
- hypothesis testing;
- qualitative and quantitative analysis;
- weighting techniques; and
- reproducible analytical frameworks.

4.3 These methodologies are supported by extensive peer-reviewed academic literature, including publications such as the International Journal of Market Research[3] (IJMR).

3 https://journals.sagepub.com/home/mre

4.4 The commercial or applied nature of the research should not diminish its scientific character where recognised scientific methodologies are employed.

5 Adherence to Ethical Standards

5.1 Adherence to ethical and professional standards is a mandatory and foundational component of the sector.

5.2 Research organisations routinely operate under internationally recognised ethical frameworks, including the ICC/Esomar International Code on Market, Opinion and Social Research and Data Analytics, and the European Pharmaceutical Market Research Association (ephmra) Code of Conduct[4], together with national professional codes, sectoral self-regulatory mechanisms, and ethical guidelines, such as the Esomar/WAPOR Guideline on Opinion Polls and Published Surveys[5]

5.3 These frameworks mandate the following:
- Scientific integrity;
- Participation protection;
- Confidentiality;
- Transparency;
- Data protection compliance; and
- Methodological reliability.

5.4 A central question in assessing the draft Guidelines is whether they apply the concept of "scientific research" in a neutral and consistent manner across different types of organisations. In particular, it is important to consider whether the assessment would change solely because the same activity is carried out by a commercial research organisation rather than by a university, public authority, or non-profit institution. This issue arises across several examples in the draft Guidelines, including:
- Examples 5 and 6 (further processing and ancillary processing);
- Examples 9 and 10 (publicly available data);
- Examples 13 and 14 (information obligations); and
- Examples 16 and 17 (derogations from transparency obligations).

5.5 In many instances, the same underlying activity could be undertaken in an identical manner by a commercial market or social research organisation, using equivalent methodologies, safeguards, governance arrangements, and ethical standards. The examples nevertheless create uncertainty as to whether such activities would continue to qualify as scientific research when conducted in a commercial context.

5.6 These risks create an implicit preference for academic or public-sector institutions. Left unclarified, the current drafting may cause uncertainty and fragmentation across Member States, with supervisory authorities potentially applying inconsistent

4 https://www.ephmra.org/sites/default/files/2025-09/2025%20EPHMRA%20Code%20of%20Conduct%2030.9.25.pdf
5 2026-06-12 - Polling Guideline_Esomar-WAPOR_Final.pdf

or overly restrictive interpretations that exclude legitimate scientific research conducted in commercial settings.

5.7 Such interpretations of research risk excluding legitimate scientific research conducted in commercial settings, even though this research plays a critical role in informing innovation, market efficiency, and evidence-based policymaking. A clear and neutral framework is therefore essential to ensure that all forms of bona fide scientific research — regardless of the institutional setting — can continue to contribute to Europe's knowledge economy and societal progress.

6 Verifiability and Transparency

6.1 We agree that scientific research should be capable of scrutiny, criticism, validation and replication where appropriate. Transparency regarding research objectives, methodologies, analytical approaches and limitations is an important characteristic of high-quality research and contributes to scientific integrity.

6.2 However, the Guidelines risk placing undue emphasis on public dissemination of research outputs as an indication of scientific research. While these mechanisms are common within academic research, they are not universally applicable across all forms of scientific research recognised by the GDPR.

6.3 A significant proportion of privately funded, commercially commissioned, market, opinion and social research cannot be publicly disclosed due to confidentiality obligations, contractual commitments, intellectual property considerations, trade secrets, competition concerns, or the sensitive nature of the information being studied. This is particularly common in sectors such as healthcare, pharmaceuticals, technology, consumer goods, financial services, and public policy research.

6.4 In the case of market, opinion and social research, there are also established systems of professional self-regulation, such as the ICC/Esomar Code of Conduct and national codes and complaint procedures, that help safeguard against any perceived or actual misuse of the research process for purposes other than genuine research. These frameworks provide accountability and oversight, helping to ensure that research activities are conducted in accordance with recognised ethical and professional standards, even where the underlying research outputs are not publicly disclosed.

6.5 The inability to publish research findings publicly should not, in itself, undermine the scientific character of the activity where the research is conducted using recognised scientific methodologies, appropriate governance arrangements, documented procedures, and quality assurance mechanisms.

6.6 We are particularly concerned by the statement that research activities should allow hypotheses, methods, data and conclusions to be open to criticism, "normally following peer review". While peer review is an important quality assurance

mechanism in academic publishing, it is not a mandatory requirement for scientific research generally and should not be presented as a normative benchmark against which all forms of scientific research are assessed.

6.7 In practice, scientific quality may be demonstrated through a range of alternative mechanisms, including:

- methodological review;
- internal scientific governance processes;
- professional and ethical oversight;
- replication and validation procedures;
- client review and challenge processes;
- external audits;
- compliance with recognised professional standards and codes of conduct; and
- publication of methodological approaches without disclosure of confidential findings.

6.8 We therefore recommend that references to peer review be revised to make clear that it is one possible mechanism for quality assurance rather than a characteristic that will normally be present in all forms of scientific research.

6.9 Paragraph 102 within the Guidance is particularly helpful in recognising that, in some research contexts, transparency must be balanced against the need to preserve methodological integrity. This is important for blind and double-blind studies, where disclosing certain information too early may bias participant responses, distort findings, or undermine the validity of the research. We recommend that the Guidelines expressly acknowledge that proportionate limitations on the timing or level of detail provided to participants may be justified where necessary to protect the scientific validity of the research, provided that appropriate safeguards, ethical oversight and post-research information are in place.

7 Attribution of responsibility (controller and processor)

7.1 We welcome the discussion of roles and responsibilities within research ecosystems. However, the Guidelines should recognise more explicitly the diversity of operational models that exist within research.

7.2 The allocation of controller, joint controller and processor roles within market, opinion and social research ecosystems is often highly fact-specific and may not always be readily characterised through a simple application of the GDPR's role definitions. Research projects frequently involve multiple actors, including commissioning clients, research agencies, sample providers, fieldwork providers, analytics providers and technology platforms, each exercising differing levels of influence over particular processing activities. As a result, responsibility and decision-making are often distributed across the processing chain in ways that require careful assessment of the actual circumstances of the processing.

7.3 We are concerned that, in practice, there is a tendency to assume that commissioning clients will invariably act as controllers because they initiate a research project and define the overarching business question being addressed. However, such an approach risks oversimplifying the analysis required by the GDPR and may not fully reflect the principles set out in the EDPB Guidelines 07/2020 on the concepts of controller and processor. As the EDPB has recognised, the determination of controllership requires an assessment of the actual influence exercised over the purposes and essential means of the processing, rather than reliance on formal roles or commercial relationships alone.

7.4 In many market, opinion and social research projects, research service providers exercise substantial autonomy in determining the research methodology, sampling approach, questionnaire design, fieldwork processes, quality controls, analytical techniques and other operational elements necessary to conduct the research in accordance with recognised professional and scientific standards. In some cases, commissioning clients may receive only aggregated or anonymised outputs and may never have access to identifiable personal data collected during the research process. Equally, research service providers are often best placed to manage data subject requests and other compliance obligations where they retain access to identifiable data and control the relevant operational processes.

7.5 The allocation of roles may also vary across different stages or components of a single research project. For example, a research service provider may process personal data on behalf of a commissioning client in relation to certain activities while simultaneously acting as an independent controller for other activities that it determines autonomously, such as quality assurance, fraud prevention, methodological validation, panel management, or compliance with professional and ethical obligations. This illustrates the importance of assessing individual processing operations rather than applying a one-size-fits-all or single role designation across an entire project by default.

7.6 We therefore encourage the EDPB to recognise more explicitly the diversity of operational models that exist within market, opinion and social research and to emphasise that role allocation should be determined through a contextual, case-by-case assessment of the specific processing activities undertaken. Such an approach would be more consistent with existing EDPB guidance and CJEU jurisprudence and would provide greater legal certainty for organisations operating within complex research supply chains.

7.7 Additional guidance or examples illustrating the application of controller, joint controller and processor concepts within market, opinion and social research environments would be particularly valuable. This would help organisations assess their responsibilities more accurately, support consistent application across Member States, and ensure that accountability is allocated to those actors exercising genuine influence over the relevant processing activities.

8 Clarification and Corrections

8.1 There are some sections of the Guidelines which require additional clarification and/or correction:

- We welcome clarification of paragraph 144, which states that the allocation of responsibilities between joint controllers must be laid down in an agreement that "must be made available" to data subjects. It is unclear whether this refers to making the agreement itself available, or whether it is sufficient to make available the essence of the arrangement, consistent with Article 26 GDPR. Clarification on this point would assist organisations in implementing joint controller arrangements in a practical and proportionate manner.

- We would welcome further clarification of the relationship between paragraph 108, fourth bullet, and paragraph 110, second bullet of the Guidelines. As currently drafted, it is not clear how the EDPB expects organisations to distinguish between information that may be withheld or delayed in order to preserve the integrity of the research, and information that must nevertheless be provided to data subjects to ensure fair and transparent processing. Clearer guidance on how these provisions interact would assist research organisations in balancing transparency obligations with the need to avoid compromising research validity.

- Similarly, the final sentence of Example 25 would benefit from further clarification. The statement that the partners to the research consortium are joint controllers "only in their respective constellations" is difficult to understand.

- Paragraph 39 should be corrected to avoid describing research incentives as "remuneration". In market, opinion and social research, incentives are used to encourage participation, support inclusion of diverse participant groups, and recognise inconvenience or out-of-pocket costs. They are not payment for opinions, data, or time worked, and should not be characterised as "remuneration". Using the term "remuneration" risks creating confusion about the nature of research participation and is wholly inconsistent with established professional and ethical practice across the sector.

9 Anonymisation and Safeguards

9.1 We welcome the emphasis placed on anonymisation and pseudonymisation as important safeguards under Article 89 GDPR. However, the wording of paragraph 161 may be interpreted as creating a de facto obligation to adopt the most advanced anonymisation techniques available at any given time, regardless of the risks presented by the processing activity.

9.2 Such an interpretation would be difficult to reconcile with the GDPR's risk-based and proportionate approach and could create uncertainty for long-term and longitudinal research projects that rely upon stable and well-established anonymisation or pseudonymisation methodologies.

9.3 Market, opinion and social research has long relied upon robust technical and organisational measures designed to ensure that research findings are analysed and reported in aggregate form and are not used to make decisions about identifiable individuals.

9.4 In many research settings, strong pseudonymisation combined with appropriate organisational separation measures can significantly reduce risks to individuals while preserving the scientific validity and utility of the research. Where identifiers are segregated, access controls are strictly managed, and different actors have access only to the information necessary for their role, the practical risks to data subjects may be substantially mitigated even where full anonymisation is neither feasible nor appropriate for the research purpose.

9.5 We therefore encourage the EDPB to clarify that the assessment of anonymisation measures should remain risk-based, proportionate and context-specific, taking account of the nature of the research, the safeguards implemented, and the realistic risks of re-identification.

9.6 We also encourage the EDPB to provide further guidance regarding the relationship between anonymisation and pseudonymisation in light of recent case law, including the implications of the Court of Justice's judgment in *Single Resolution Board v EDPS*. Additional discussion of how the availability of identifiable information to different actors may affect the assessment of personal data status, controllership and safeguards would be particularly valuable in complex research environments where different participants in the processing chain handle large amounts of personal data and have access to different categories of information.

10 Codes of Conduct

10.1 We recommend that paragraph 171 of the Guideline is expanded to include a practical example demonstrating how approved or recognised sectoral codes of conduct, professional rules and self-regulatory mechanisms can operate as safeguards supporting responsible scientific research under Article 89 GDPR.

11 Conclusion

11.1 EFAMRO and Esomar support the EDPB's objective of providing greater legal certainty regarding the application of the GDPR to scientific research.

11.2 However, the final Guidelines should more fully reflect the broad interpretation of scientific research required by Recital 159 GDPR and avoid creating the impression that scientific research is confined primarily to academic, public-sector or clinical settings. Research is not only a tool for understanding societal trends and behaviours; it is also a fundamental driver of societal and economic growth within the European Union. High-quality market, opinion, and social research support employment, production, innovation, and investment by helping you make informed decisions that align products, services, and policies with consumers' needs and preferences. The

research sector provides robust, evidence-based insights that help businesses and public authorities make decisions that foster competitiveness, economic development, and societal well-being. As such, research activities — whether conducted in academic, public, or commercial settings — play an essential role in strengthening the EU's internal market and promoting sustainable growth.

11.3 Market, opinion and social research is capable of satisfying the characteristics identified by the EDPB Guidelines and frequently does so through the application of recognised scientific methodologies, robust ethical standards, independent governance arrangements and comprehensive data protection safeguards.

11.4 We therefore encourage the EDPB to:

- clarify that the indicative factors are non-cumulative and non-mandatory;
- recognise more explicitly the legitimacy of privately funded, applied, market, opinion and social research;
- adopt a proportionate approach to transparency and anonymisation requirements;
- provide additional examples involving commercial research environments; and
- recognise established sectoral codes and governance frameworks as a method of supporting ethical scientific research.

11.5 These changes would strengthen the EDPB Guidelines, improve legal certainty, promote consistent application across Member States, and better reflect the broad and technologically neutral conception of scientific research established by the GDPR.

12 General

12.1 *Gender pronouns*

To improve inclusivity of the document gender pronouns e.g. his/her should be replaced with terms such as 'their'. See clause 37, 123 and 163.

12.2 *Typos*

There are some typos in the document:

- Footnote numbering within the main body of the text where the font needs to be reduced - clause 27, 32 (x3), 57 (x2), Example 12, 137 and 140
- Clause 146 - remove 'of' in the first sentence.
- Clause 171 - 'and' in the first sentence needs the font adjusting.

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Annex A

Examples of Market, Opinion and Social Research that qualify as scientific research

Example 1

Longitudinal Case Study

Background

The population in Ireland is ageing, the estimated population aged 65 or over in ROI is estimated to have reached 768.9 thousand in August 2022 (www. Statista.com). The number of those aged 80 or over is also expected to rise in the next ten years. In stark contrast to the evident importance of ageing, there is a lack of social, economic and health information on older persons in Ireland. This information is essential to enable forward planning and to ensure a "healthy and happy" life span in later life. Against this background the client felt there was an urgent need for accurate and representative health and socio-economic data.

Project Description

The method used to select participants for the study was designed to ensure that the sample would be representative of the Irish population aged 50 and over. A random stratified sample of circa 5,500+ participants aged 45-64 years are recruited with informed consent. The market research organisation provides a consent and information guide which participants must sign by way of consent captured electronically and by signed paper copy which is retained by the market research organisation.

The study is conducted every two years ethics approval is gathered by the client who is the controller. Each wave involves conducting interviews from all individuals who participated in a previous wave of the study and have agreed to participate in subsequent waves. The previous data collected from earlier waves of the study, is fed through on the research questionnaire to enable interviewers working for the market research organisation to identify how things have changed for each participant interviewed, thus data is linked at an individual level for the survey. The market research organisation and its interviewers are processors who complete the project following direct instruction from the client.

The identifiable data is collected by the market research organisation and shared with the client. Results from the research are published and shared to improve understanding of ageing and the needs of older segments of the population. When reporting the data, the client aggregates and anonymises the personal data collected from participants.

All personal data is retained and stored by the market research organisation, to enable comparisons to the made between waves of the research project. Any data subject requests are fulfilled by the market research company.

Example 2

EPHMRA: Examples of healthcare market research which may qualify as scientific research, or in general meet a sizable share of the criteria (i.e., consent, etc).

Unmet medical needs

A Bio/Pharmaceutical organisation seeks to understand current medical needs to help prioritise R&D efforts. The company carries out market research amongst Key Opinion Leaders (KOLs) and relevant specialists across a range of conditions to identify and understand where the gaps are, i.e., limited or no new effective treatments. This might include a sizing and prioritisation exercise to help the company focus resources to conditions most in need of new bio/pharmacological interventions. The market research would rely on consent from KOLs and specialists to share their opinions on their disease or condition of expertise.

Context

Pharmaceutical organisations conduct this type of market research when looking to prioritise R&D effort and budget (perhaps reprioritise their product portfolio). Additionally, companies may conduct market research to evaluate the unmet medical needs in a therapy area they already have products in, e.g., oncology, autoimmune disorders, to prioritise resources.

Example 3

Target Product Profile Testing

A Bio/Pharmaceutical organisation seeks additional information from relevant experts on a drug they have in development to help refine the product profile and input to clinical development. A qualitative market research study is undertaken with relevant KOLs and specialists in the disease area(s) under investigation. The study seeks experts' views on the condition and anonymised product profile (Target Product Profile or TPP) shown during the research.

Context

This type of research is essential for clinical development, for example, to assess product attributes such as efficacy, safety, mode of administration, mode of action, relative to current 'gold standard' therapy. Medical and clinical specialists provide the TPP to ensure balanced and clear information, as well as anonymising the TPP and classifying the activity as for market research purposes only (clearly identifying that the activity is not a disguised promotion). This type of study is scientific in nature and meets sizeable share of the criteria (e.g., consent, etc).