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European Data Protection Board
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Feedback on Guidelines 1/2026
on processing of personal data for scientific research purposes

Introduction:

noyb – European Centre for Digital Rights is a not-for-profit organisation active in the field of the protection of data subjects' rights and freedoms. We welcome the EDPB's efforts to provide guidance on the intricacies of using personal data for scientific research purposes ("Guidelines") and the opportunity to provide feedback and proposals for improvements.

We consider that the following aspects, listed in the order they appear in the guidelines, are the most important points that require clarification and/or improvement:

1. The background under the Charter.
2. The six conditions for a processing operation to qualify as fulfilling a "*scientific research purpose*".
3. Further processing of personal data for a scientific research purpose.
4. How data processing for a scientific research purpose can be based on the legal basis of consent.
5. Whether "science" itself can constitute a legitimate interest.
6. How information obligations in Art 13 and 14 function in the face of scientific research.
7. When the right to object under Article 21(6) GDPR is applicable.

Our detailed comments on these aspects are as follows:

1. The background under the charter

First and foremost, we want to highlight that any limitation of the right to data protection under Article 8 of the Charter must have an aim in the genuine public interest and be overall proportionate.

While Article 13 of the Charter mentions the general freedom to conduct scientific research, the core of this right is that governments do not interfere with the content of academic works. It does not grant academia a general option to bypass the rights of others. Hence, any overly broad exemptions (e.g. from the fairness and hence the transparency principle or the principle of purpose limitation that are all enshrined in Article 8(2) of the Charter) would risk that privileges in the GDPR would go too far and hence risk not being proportionate under Article 52 of the Charter anymore. This could have the unintended consequence, that even *legitimate* research would loose such privileges via an anullment procedure if any exemption is too broad.

There is hence a need to craft a delicate line beween privileges in the *genuine* public interest and purely commercial interestes to evade the right to data protection and the GDPR.

2. Key-indicative factors for scientific research purposes:

It is welcome that the EDPB has attempted to define and delineate when processing under the GDPR is done in the name of science and when it is not. To this end six criteria are stipulated, that when fulfilled will lead to a presumption that the processing at hand is conducted for a scientific research purpose. These criteria seem generally appropriate to define what falls into the scope of the privileged research purposes. However, some of the conditions might need further clarification as to their interpretation and the concrete practices required:

- The requirement of compliance with ethical standards seems to pose a problem when such standards either do not exist (e.g. on AI) or are drafted by controllers themselves (leading to obvious conflicts of interests). It must be clear that such forms of "self-regulation" cannot replace the requirements of the GDPR and the Charter and are only a bare minimum requirement.
- We also refer to the criteria of autonomy and transparency, for which further guidance on how this criterion can be fulfilled should be provided: For example, the mentioned methods for transparency should be further explained because the "peer review" method might not always be used for various reasons, or the mere claim that publication is in principle intended "in the future" should not be sufficient.
- We also want to highlight that any definition should include the need to make results available to the general public. It is hard to see how purely internal research would benefit society overall and hence fall under the definition of a public interest in Article 52 of the Charter. In this respect we think that the definition on point (v) that scientific may "also" further commercial interests is useful, as it (at least) requires a dual purpose of public and private interests and excludes research for purely private gain.

3. Presumption of purpose compatibility - further processing

In para 22 of the guideline the following is stated:

> *"In many cases controllers will be able to rely on the same legal basis, for example where a controller initially processed personal data on the basis of public or legitimate interest. It is, however, not always possible to rely on the same legal basis when further processing personal data for scientific research purposes. This applies in particular if the initial legal basis for the primary processing is consent or a legal obligation."*

While it might be possible to rely on the same legal basis for processing data for a scientific research purpose as was relied on for the collection purpose, it should be clarified that further processing for any purpose (including scientific research) requires a separate legal basis under Article 6(1) GDPR and the initial legal basis cannot automatically justify the further processing.

For example, when a data subject provides information about his HIV status based on a specific consent that this may only be used for a specific study, it would be contrary to the explicit wish of the data subject if such data would be processed further for other purposes based on a (clearly limited) consent.

Due to the uncertainty (in particular, due to the misleading non-binding Recital 50 GDPR) this should be clarified in the Guidelines mentioning that the principle of lawfulness as being applicable is welcomed but, in our opinion, not sufficient.

4. Consenting to Scientific research

In section 4.1 of the Guidelines there are several elements that seem to be in conflict with the requirements of consent under Article 6(1)(a) in connection to Articles 4(11) and 7 GDPR.

In paragraph 38, the EDPB correctly points out that the processing of personal data for the purposes of providing healthcare must not be conditioned on the data subject's consent to the processing of their personal data for research purposes. However, the EDPB states in the same paragraph that a single consent for scientific research and the provision of healthcare can be obtained in case the processing is necessary "*both for the purposes of providing healthcare and conducting scientific research, since those purposes are interrelated*." In our opinion, it should be further clarified that it is not sufficient that the purposes are "*interrelated*"; rather, a single consent should only be possible in case the purposes are so closely linked that one cannot be fulfilled without the other.

The EDPB also introduces different "types" of consent in the Guidelines.[1] The EDPB should avoid the impression that it introduces a new kind of consent that is not subject to the requirements for consent in Articles 4(11), 6(1)(a) and 7 GDPR. This is particularly true for what the EDPB now calls "***broad consent***". While we recognise that the EDPB did not invent this notion but used a term already in use and it is a common colloquial term to describe the idea of unforeseen purposes in Recital 33, we consider this term to be not supported by the law itself and therefore inappropriate to be used in official documents of the EDPB. Considering that specificity and granularity of consent are requirements of consent under the operative part of the GDPR, it is unfortunate that the EDPB would characterize (a whole type of) consent as "*broad*". This could invite controllers to rely on a concept of consent completely devoid of specificity and granularity as a legal basis. The notion of broad consent is in our view incompatible with the conditions of consent in the GDPR, both in the definition itself as well as the Guidelines on Consent published by the EDPB themselves.[2]

While we oppose the term "broad consent", we recognise that the required specificity of consent does not mean that the research activity must already be defined precisely. Similarly, in case of a consent for marketing purposes the future marketing activities might not be determined in a precise and comprehensive manner. But it would be wrong to talk about "broad consent for marketing purposes".

We suggest an alternative way of phrasing such consent which could be named "***consent to certain areas of scientific research***" in line with Recital 33. Furthermore, we suggest that the requirement in Recital 33 – namely that a more specific consent is not possible – is also reflected in the Guidelines. The non-binding Recital 33 seems to suggest an exception in a specific situation, which cannot be elevated to a general rule for any consent in the area of scientific research. If a controller knows that personal data will only be processed for a specific study, then it is absolutely a required (see "fairness" in the Charter) to also communicate that to a data subject.

[1] See para 42 and Section 4.1.2.1 and 4.1.2.2

[2] See Guidelines 05/2020 on consent under Regulation 2016/679 section 3.1.3 and 3.2

Example 8 on page 25 illustrates the problem with relying on consent this way. Here the idea is that an unknown number of recipients (university hospitals) collaborate by creating a database from data relating to patients. Each patient "consents" to their data being shared with an unknown number of recipients through a shared database between these recipients and for purposes unknown when the consent is collected. The consent given is unspecified in who will have access to the patients' data (as well as for what reasons and how this data will be used). In particular not knowing the identity of controllers (what apparently can also be switched out at any time) makes it hard to argue for a valid consent in this case. Apparently, the Guidelines try to incorporate some kind of data donation that is not foreseen in the GDPR.

If anything, this example thus illustrates how dysfunctional consent is as a legal basis when processing personal data for scientific research purposes, especially in the field of medicine.

Regarding what the EPDB calls "dynamic consent" in paragraphs 51-52, this concept would need further explanation by use cases because the Guidance is not sufficiently clear when this exemption could be applicable. However, if consent was the legal basis justifying processing for scientific research purposes any further processing for scientific research purposes with said data is unlikely to be possible without further consent for such processing from the data subject.

5. Legitimate interest as legal basis for scientific research

In section 4.3 of the Guidelines, the EDPB states that *"[s]cientific research and the accompanying processing of personal data can be a legitimate interest under Article 6(1)(f) GDPR*". It is important to point out that – as specified in the Guidelines 1/2024 on processing based on Article 6(1)(f) – a legitimate interest must be clearly and precisely articulated. A vague or general description is not sufficiently articulated. In order to invoke a legitimate interest, it is therefore necessary, to further describe the specific research purpose. This should be reflected in section 4.3. accordingly.

Furthermore, we are concerned that the EDPB mentions that this legitimate interest would have some form of "*significant weigh*" to the interests of controllers. We highlight that Article 6(1)(f) GDPR must be read in light of the overall proportionality principle of the Charter. By default, fundamental rights prevail over other interests – unless the outweigh these fundamental rights. Research by itself is not "more" of a legitimate interest than other interests (e.g. the interest in protecting property, health or safety) that the EDPB has rightfully required to be balanced with the right to data protection.

The current wording could be understood in a way that research is a "super legitimate interest", which may be understandable from a political side (as it may be less contentious), but cannot logically be higher ranking than the right to protect security, health of property. We urge the EDPB to ensure that its Guidelines stay consistent in this respect as controllers could otherwise deduct that if research already carries "*significant weight*" then other purposes must carry even more weight.

6. Information Obligations Article 13 and 14

The information obligations in Articles 13 and 14 GDPR differ when it comes to further processing for scientific research purposes, in that Article 13(4) contains no exeption in the duty to inform data subjects when processing for further purposes and Article 14(5)(b) does.

Therefore it is incorrect to suggest that controllers can rely on providing information "indirectly" to data subjects when Article 13 GDPR applies, as the EDPB does in para 89 of the Guidelines. This should be remedied. The basis for the statement seems to be a suggestion by the European Commission to change the information obligation in Article 13 GDPR specifically relating to further processing for scientific research purposes. The suggesting is however not law and should not be the basis for the current Guidelines.

We also want to stress that Articles 5(1)(b), the information under Articles 13 and 14 and then the right to object in Article 21(6) GDPR form a logical chain towards some form of information / ”opt-out” system for secondary use. When removing the ”middle part” of that chain, data subjects may not be informed properly and are hence unable to exercise their right to object in Article 21(6) GDPR. This could overall call the privilege in Article 5(1)(b) GDPR into question from a Chater perspective.

Example 14 on page 36 is supposed to explain that an actor can be the controller even though it does not hold or process personal data. However, it would be helpful if the EPDB would also clarify the retail analytics company’s role and the fact that the univeristy (as well as the analytics company if it acts as a controller) is obliged to inform data subjects in accordance with Article 14 GDPR.

In para 92, the EDPB refers to ”information chains” in which one controller provides information in accordance with Article 14 GDPR for a seperate controller. It should be pointed out, that a simple ”hiding” a link to a seperate controller’s privacy policy is not suficcient to comply with the second controller’s information obligation. Otherwise, this could lead to chains in which privacy policy A links to privycy policy B which links to privacy policy C and so forth – while the data subject did not even open privacy policy A. If a controller wants to provide the information in accordacne with Article 14 GDPR for another controller, the link to the other controller’s privacy policy should be provided to the data subject in the first layer.

In example 17 on page 43, the EDPB refers to a staturory obligation of secrecy as a reason not to provide the information under Article 14 GDPR. However, we recommend furhter mentioning in the example, that the statutory obligation is regulated in national or EU law.

In para 102-103 the EDPB identifies that there are exemptions to the information obligation under Article 14 (for ”covert research”). Situations when these exemptions apply will invariably lead to loss of control of personal data for the data subject, and thus constitute a real loss of rights for those data subjects. Given that Article 13 and 14 GDPR are part of the fairness principle in Article 8(2) of the Charter, we again have to stress that limitations must be proportionate and e.g. balanced by later information or similar approaches.

The examples listed in the Guidance, like risk of bias or of loss of quality of data („provision of information to data subjects may introduce bias to the research or otherwise negatively affect the quality of the personal data that is collected”) are not clear enough but could lead to too broad interpretation, thus should be re-considered and redrafted .

7. The right to object

In para 125 of the guideline the EDPB states that:

> *”Article 21(6) GDPR, is not limited to public interest in the meaning of Article (6)(1)(e). A controller relying on legitimate interest, pursuant to Article 6(1)(f) GDPR, can also reject an objection under Article 21(6) if the controller can demonstrate that the processing of personal data for scientific research purposes is a legitimate interest that coincides with a public interest”.*

noyb rejects this notion. It is not enough that processing personal data for scientific research coincides with a public interest for a controller to be eligible to reject an objection request. The scientific research must be ”*necessary for the performance of a task carried out for reasons of public interest*”. The conditions in Art 6(3) GDPR therefore apply, including legislation that is both proportional and meets an objective of public interest.

8. Conclusion

We consider that the Guidance contains useful clarifications but still needs significant improvements as detailled above.

We also underline that in the ligh of the ongoing legislative deliberations on the proposed Digital Omnibus which inlcudes a definition of ”scientific research” in the proposed Article 4(38) GDPR and a proposal for amending the information obligations in Article 13(5) in case of scientific reserach, the Guidance requires very careful consideration by the EDPB.

We understand that the EDPB may feel under political pressure given the proposals in the Digital Omnibus, however, we also want to stress that a mere suggestion by the European Commission is not the law – and Guidelines must be based on the current text of the GDPR and neither on non-binding Recitals (when they are contrary to the text of the GDPR) nor on political aspirations.

We hope that our comments will be taken into account and remain at the EDPB’s disposal for further information or clarifications of our comments.