Comments on the EDPB Guidelines 1/2026 on the processing of personal data for scientific research purposes

This document sets out the comments of Wellbeing Services County of Pirkanmaa (Pirha) Finland on the published EDPB Guidelines 1/2026 on the processing of personal data for scientific research purposes. The comments have been prepared as Pirha's contribution to the ongoing public consultation and are intended to highlight practical and regulatory issues of particular relevance to research conducted in the Finnish healthcare and wellbeing services context.

1. The guidelines should include a clear and practical description of dynamic consent in scientific research. In particular, they should specify how dynamic consent operates in long-term medical research where research questions or phases evolve over time, as well as the practical procedures by which data subjects are kept informed and, where necessary, asked to provide renewed consent.

2. The guidance on storage periods should be clarified so that the storage period or the criteria used to determine it are described in concrete terms. A mere reference to "necessary research purposes" is not sufficient. In addition, it should be expressly stated that the storage period must be consistent with national legislation.

3. The guidelines should make a clear distinction between patient records and research data. Patient records created within a healthcare unit are subject to mandatory national retention obligations that cannot be altered by contract, whereas the retention of research data is subject, at least in part, to different assessment criteria.

4. The guidelines should clarify the required level of specificity for defining future research purposes or research areas. In particular, it should be explained whether a general reference to medical research is sufficient, or whether the purpose must be limited more precisely to a specific disease area or field of research.

5. The guidance should better take into account long-term and unforeseeable further use for research purposes. From the perspective of scientific development, it is important to enable the use of already collected data in future research settings that may be difficult to

foresee at present, while remaining within the limits of purpose limitation and appropriate safeguards.

6. The guidelines should clarify how the retention of data for future research purposes is to be assessed in the case of research data lakes, register-based studies, or other arrangements in which patient or client data are collected, stored, or transformed for research use separately from care purposes. In such situations, it is important to describe clearly the conditions under which retention is permitted and when processing can no longer be based on the original care purpose.

7. The guidelines should more clearly indicate their intended audience and the types of actors referred to as controllers. In particular, it would be useful to distinguish between research groups, healthcare units, university hospitals, and other organisations acting as research controllers, data holders, or both.

8. The guidelines should address more explicitly register-based research and regulatory frameworks comparable to Finland’s Act on the Secondary Use of Health and Social Data. The current examples focus on consent-based research and do not provide sufficient guidance for situations where personal data are used for research on another legal basis.

9. In addition, it would be useful to provide separate guidance for organisations that retain data collected for primary purposes and subsequently make them available for research use, such as university-affiliated wellbeing services counties and university hospitals.

10. The guidelines should clarify how the legal bases of public interest or the exercise of official authority, as well as legitimate interests, apply in the research context across different actor roles, including the roles of controller and data holder.

11. The section on transparency obligations should clearly define the types of controllers to whom the various obligations are addressed. For example, the possibility of allowing voluntary contact details for future contact requires more precise targeting depending on the type of research and the nature of the controller.

12. The guidelines should clarify how transparency obligations apply where personal data were originally collected for another purpose and are later used for scientific research. In particular, they should explain when general notice is sufficient and when an individual

notification to data subjects is required, as well as how national special legislation affects the assessment.

13. The guidance on long-term studies should allow case-by-case discretion regarding contact channels. In many studies, electronic contact may be the most practical and secure option, whereas telephone and postal contact may impose disproportionate burdens in large-scale studies and also involve risks of contacting the wrong individual.

14. The guidelines should assess more carefully the need to retain contact details for transparency purposes in light of the data minimisation principle. If contact details are not otherwise needed, it is important to specify on what basis their retention is permitted and how this relates to pseudonymisation and Article 11 of the GDPR.

15. It would also be necessary to clarify which means and data sources a controller may use when obtaining a data subject's contact details in order to fulfil transparency obligations. In the healthcare context in particular, it should be assessed whether contact details may be retrieved from patient information systems for research-related transparency purposes or whether the search must be limited to public sources or other specifically permitted channels.

16. The guidelines should clarify the application of the rules in situations where research data are collected both directly from the data subject and from registers. Such combinations are common in research, and it would be useful to provide explicit interpretative guidance on transparency and data subject rights in these situations.

17. The guidance on categories of recipients should be made more specific. The guidelines should describe how precisely recipient groups must be identified to data subjects and when expressions such as "new research partners", "other research groups", or "laboratories analysing samples" are sufficiently specific.

18. Similarly, it would be necessary to clarify how precisely the categories of personal data processed in the research, and changes relating to them, must be described to data subjects. It would be useful to explain whether a general reference to health data is sufficient or whether more specific information should be provided, for example on laboratory results and diagnoses.

19. The guidelines should include more concrete examples of types of changes that are typical in research, especially in long-term projects. These could include, for example, new

research partners, changes in a researcher’s organisational affiliation, or changes in the practical implementation of personal data processing.

20. With regard to freely given consent, the guidelines should assess more carefully situations in which consent is requested by the patient’s own physician or another person involved in the care relationship. In such settings, it is important to explain how voluntariness is ensured in practice.

21. The guidelines should clarify the normative status of the examples: whether they constitute binding interpretative guidance or merely illustrative examples of possible approaches.

22. The section on controllership should clarify the roles of the sponsor, the research organisation, the researcher, and any partners. In particular, it is important to specify when a statutory sponsor role implies controllership and how this relates to situations where there are features of joint controllership in the research.

23. The guidelines should also state more concretely that, in scientific research, controllership is determined by who in practice defines the research questions and the means of processing, that is, who exercises control over the research plan.

24. In addition, it is important to clarify what is meant by a researcher’s affiliation and when an independent researcher may act as a controller. This has particular practical significance for students, grant-funded researchers, and researchers working without an employment relationship. At the same time, it should be made clear that possible controller status does not automatically confer a right to obtain registry data unless the disclosing organisation has assessed the recipient’s capacity to ensure data security and fulfil the obligations of a controller.

25. The guidelines should also address more extensively changes in controllership during the course of a research project, such as the entry of new partners, the transfer of a project from one organisation to another, or situations in which control over the research plan changes.

26. The assessment of joint controllership should be clarified, especially in the context of research consortia. It would be useful for the guidelines to describe how much actual or

potential influence over the research plan is required for a party to be regarded as a joint controller.

27. The guidance on anonymisation should clarify whether it is sufficient to inform participants that the data will be anonymised, or whether they should also be specifically informed that, after anonymisation, they can no longer obtain personal information about the processing or exercise all data subject rights in the same way as before anonymisation.

28. In addition, it would be useful for the guidelines to assess more recent case law and its implications for scientific research. In particular, it would be necessary to clarify how the status of pseudonymised data should be assessed in relation to third parties who have no means of identifying the data subjects, and what transparency obligations apply to such transfers in the research context.

Helsinki

June 16th 2026

Kati Kristiansson

Director of Research and Development