PANELFIT

PARTICIPATORY APPROACHES TO A NEW ETHICAL AND LEGAL FRAMEWORK FOR ICT

Issues and gaps analysis in the context of ICT research and innovation

INFORMED CONSENT

Is there more than one legal basis for data processing?

Issue: Ambiguity of the GDPR → Is it legally acceptable to have more than one legal basis for data processing (e.g. consent and legitimate/public interest)? The general rule seems to be that a research entity might not be able to switch legal bases if one basis is no longer available, except where an authoritative body has issued an opinion, guidance or ruling.
Impact on R&I: Research entities must determine which legal basis is used for the intended research and prepare to respond should the legal basis be removed.
Mitigation measures: Guidelines

Easy obtainment of consent versus freedom of consent

Issue: Imbalance between the data subject and the data controller, particularly when the controller is a public authority or a large entity (e.g. tech companies). Obtaining consent has become extremely easy (e.g. banners), and experts are questioning the value of consent as a means to protect individuals.
Impact on R&I: Consent must be freely given, specific, informed and unambiguous and indicate the subject's agreement to the processing of their personal data. Researchers may not always be able to fulfil these requirements.
Mitigation measures: Guidance and tools from EDPB or EDPS.

Consent for participation in research projects and as a legal basis

Issue: Consent for participation in research projects and consent as a lawful basis should be separate and different. Data subjects must understand that they are granting consent for two separate matters, and that their consent can be revoked independently for the research.
Impact on R&I: The research entity has to be able to comply with the data subject's request.
Mitigation: The differences must be clearly emphasized by the institution carrying out the research. Codes of conduct, with best practices and template forms.

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Foreseeing all use cases versus broad consent

Issue: How should the research entity inform the data subject about the future purposes?
Impact on R&I: A research entity might choose to obtain very broad consent. However, this would be ethically questionable and in contradiction with the law.
Mitigation: Guidelines for researchers should clarify that, when obtaining consent, the purposes should not be too general or broad - but at the same time, in cases of further purposes, safeguards should be adopted (e.g. clear information notice updates, easy opt-out mechanisms, etc.).

The issue of other data subjects

Issue: It is possible that when collecting personal data about an individual, the data controller is also collecting personal data from other persons related to him/her (e.g. genetic data → information about relatives)
Impact on R&I: Research entities would have to inform all other related data subjects. However, in many cases, they will be unaware of these duties, or incapable of contacting these individuals.
Mitigation: Guidelines.

Ineffective information duties

Issue: Information notices are often ineffective at actually informing data subjects of the risks and details of data processing. Article 12(7) of the GDPR encourages providing information via icons.
Impact on R&I: Clear information is a necessary safeguard to adopt in case of research data processing according to Article 89 of the GDPR.
Mitigation: Guidelines + development of a list of icons by the EC + templates for data-flow diagrams

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Anonymous versus pseudonymous data

Issue: a. anonymized data can more and more be transformed back into personal data. Potential risky situation where data is processed as if it were anonymous when it is actually pseudonymous. **b.** pseudonymized data can be considered anonymous when certain characteristics have been met and, consequently, fall outside of the GDPR. The same set of data would be personal for some researchers and anonymous for others.
Impact on R&I: If the supposedly anonymized data turns out to be personal data, the researcher would need to have a legal basis to process it, such as informed consent.
Mitigation: a. An authoritative body should clarify criteria to determine if information is properly anonymized. **b.** Researchers should conduct anon/pseudonymisation audits when receiving third-party datasets. **c.** Researchers should treat any data related to individuals as personal data.

Different national legislations on research within Europe

Issue: Risk of 'forum shopping': research initiatives locate their main research partner in Member States with looser requirements.
Impact on R&I: European research projects typically operate in several different member states.
Mitigation: a. An harmonized European code of conduct (by EDPB, EC initiatives).
b. A common legal framework for research purposes, adopting the higher standards.
c. Before starting a European research project, partners should clarify which national legislation they will be following.

Potential disparity between private and public research entities

Issue: Which research entities should be considered public bodies? Researchers of public bodies would be forced to use public interest (and not legitimate interest) as a legal basis → The right to object can have different outcomes, depending if the data controller is a public or private entity. Member states may introduce more specific provisions → Situations in which some data protection rules and (stricter) safeguards apply only to research led by public entities.
Impact on R&I: A data subject could object to data processing by private research entities acting under legitimate interest, but not by public research entities.
Mitigation: a. EDPB could clarify that all research entities can process data only under consent or public interest bases, and not legitimate interest. **b.** Guidelines (EDPB).

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Processing of special categories of personal data for research

Issue: the GDPR does not provide a definition of what constitutes research and statistical purposes. Recital 159 gives a broad interpretation: technological development, fundamental research, applied research and privately funded research. Is purely private research (e.g. for marketing purposes) included in this definition? EDPS → Restrictive interpretation of "collective knowledge and benefit", not endorsed by EDPB.
Impact on R&I: Uncertainty of definitions could lead to uncertainty on the processing of special categories of personal data, and also in the application of the 'exceptions of purpose' limitation principle for research purposes.
Mitigation: Definitions by EDPB or EDPS.

Gap: lack of Member State laws for the application of Article 9(2)(j), for which besides consent it is possible to process special categories of personal data if the processing is necessary for scientific or research purposes.
Impact on R&I: In the absence of national regulations, any data processing activity for research purpose that involves special categories of personal data could only be done relying on consent.
Mitigation: An EU institution should push for the approval of national laws and to harmonize them.

Vulnerable data subjects

Issue: No agreed definition → Not all vulnerable individuals are equally protected → Up to data controllers. Vulnerable individuals might not provide free consent → Research entities have to rely on other legal bases → Vulnerable data subjects might be subject to a lesser degree of protection.
Impact on R&I: Researchers often deal with vulnerable data subjects. These could be harmed more than 'average' data subjects in case data are transferred for other purposes.
Mitigation: A clearer definition and a list.

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Deceased people

Issue: Are data on deceased people personal data? Personal data from deceased people (e.g. genetic data) could reveal data from their relatives. Rules on postmortem protection of honour should be taken into account.
Impact on R&I: If the GDPR no longer applies to personal data of deceased persons, they can be used for research freely.
Mitigation: European code of conduct for researchers. A formula to enable people to give consent to their personal data after death for research purposes, when provisions of GDPR on this topic are not enough. This formula would include consent of relatives when needed.

Scope of the DPIA and the notion of data subjects

Issue: The GDPR states that data controllers should take into account the rights and legitimate interests of data subjects *and other persons concerned*. It isn't clear who these persons might be (those who may be impacted by data processing, or people whose data might be inferred), or if and how data controllers could take those individuals into account.
Impact on R&I: From a wider perspective, all research could have an impact on other individuals, for instance through its results.
Mitigation: interpretative guidelines.

Safeguards for research purposes in Article 89

Issue: The vagueness in the terms on the list of desirable safeguards is a problem (only pseudonymization and anonymization are mentioned). No guidance on transparency.
Impact on R&I: Risk of a minimalist approach when implementing Art. 89 → Researchers could implement only data pseudo/anonymization, and ignore other safeguards. WP29 has indicated transparency as an appropriate measure to ensure compliance with Art. 89. According to it, member states could adopt specific safeguards. This means the application of safeguards might differ among them.
Mitigation: A list of safeguards, included in a European code of conduct for researchers, or in interpretative documents from the EDPB. Data anonymization should be the most encouraged safeguard. Specific practices and tools should be suggested to researchers.

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Special categories of personal data

Issue: The boundary between personal data and special categories of personal data is often blurred. Some personal data (that cannot be considered directly as a special category of personal data) might allow the researcher to infer special categories of personal data. For example, lifestyle data, (e.g. daily diet or fitness); information related to sugar or wheat → diabetes or coeliac disease; location data → sexual data, sexual orientation, political beliefs, religious beliefs, etc.

Impact on R&I: Researchers often process a large amount of data that could belong to special categories of personal data. This could oblige them to have a DPO, and to perform a DPIA. These duties would require financial and organizational efforts.

Mitigation: Alongside the issuance of guidance on this matter, the EDPB should produce regular summaries with the case law from local DPAs. As an alternative, the EDPB could clarify at which level some general criteria should be adopted to interpret the categories of personal data in Article 9(1) of the GDPR.

The content of these fact sheets comes from the "Issues and gaps analysis on informed consent in the context of ICT research and Innovation", realized in 2020 by the Vrije Universiteit Brussel for PANELFIT.

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