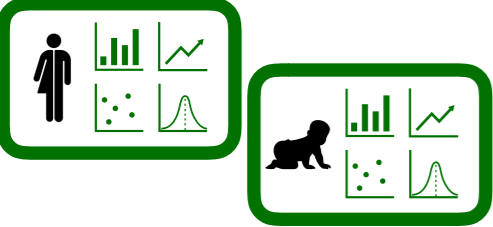


Privacy in Academic Research; A Convenient Overview For Your Privacy By Design Approach



Personal Data Collection

Direct and indirect collection of (special categories of) personal data

Personal Data Application

Including reuse (further processing) of personal data

General questions: purpose of data collection / which data necessary, given the purpose / is the processing allowed / we *could*, but *should* we?

Specific risks to assess for *collection* and *application* of personal data - collect evidence that substantiates answers to the questions below.

Risk Assessment:

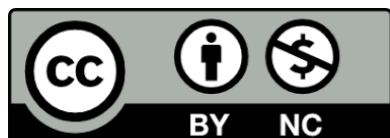
1. of the **individuals** (data subjects): are the individuals minors and / or member of a vulnerable group? Have the individuals not given their implicit consent? Are the individuals consulted prior to the collection of their personal data and do the individuals understand possible risks related to the processing of their personal data now and in the future (further processing)?
2. of the **responsible person** (controller) of the processing of personal data: is the person / organisation trustworthy, what is the track record in terms of data breaches (appropriate safeguards) and in terms of transparency? Which (ISO) standards are in place, which external audit(s) provide evidence for application of appropriate safeguards?
3. of the **personal data**: is the data quality and integrity optimal? Is the data trusted, secure and protected (encrypted, pseudonymised). Is the data sensitive (special categories of personal data)? What is the scope of the data: large scale / case study / longitudinal dataset? Is the dataset likely to be hacked, what are re-identification risks, for instance as a result of further processing and data linkage?
4. of the **processing** of personal data: is access to the data on a need to know base, is the access controlled (logged) and monitored? Is the scale of the processing large (> 10.000 individuals)? Is the processing done manually / automatically? Does the processing entail systematic monitoring of individuals?
5. of the **technologies** used when processing personal data: are privacy-invasive methods or technologies used, such as camera systems to monitor behaviour? Is sensitive information recorded? Is personal data mined (eg. data mining social media data) or 'web crawled'? Is social network analysis, or profiling of individuals and/or groups (particularly behavioural or psychological profiling) performed? Is artificial intelligence used to analyse personal data using auto mated decision-making that has a significant impact on the data subject(s)?
6. of the **third parties** collaborating when processing personal data: see (2) above and additionally: which sub contractors are used by the third party?
7. of the **geographical aspects** (cross border data transfers) when processing personal data: Do you share personal data with a third party outside the European Union, Norway, Liechtenstein and Iceland? The European Commission may have determined that this non-EU country has an adequate level of data protection, which allows you to share personal data. Otherwise, consult your privacy officer or data steward.
8. of the **legal agreement(s)** (data processing agreement / joint controller agreement / non disclosure agreement /...) ensuring proper distribution of responsibilities and accountability for the processing personal data: how soon after relevant changes are partners updated (new sub contractors, processing in other geographical areas)? In general, which concessions have been made?

Societal Effect of use of Personal Data

Reasonably Expected

Creepy

Violating Privacy Rights of Individuals and/or Groups



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- **Gender Neutral Icon** by Dan Brunson: <https://thenounproject.com/term/gender-neutral/13777/>

- European Commission, H2020 Grants Manual, **Ethics and data protection**. November 14 2018.
Online: https://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/ethics/h2020_hi_ethics-data-protection_en.pdf

- **Credits**: based on conversations with many people, but notably with Cristina Montagner, Tiemen Folkers, both University of Groningen, Marina Noordegraaf (<https://www.verbeeldingskr8.nl/>) and Khaled El Emam and Luk Arbuckle, both from Privacy Analytics (<https://privacy-analytics.com/>).

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