Scientific research and data protection

FNR Info Day
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When should you contact the CNPD?

(1/3)

- “Processing of personal data”
  - Law of 2 August 2002 on Data Protection
    (implemented Privacy Directive 95/46/EC)
  - General Data Protection Regulation
    in the future (Spring 2018)

- At the beginning of your research project
When should you contact the CNPD? (2/3)

- Research project with personal data
  - Personal data = *Information related to an identified or identifiable natural person (broad definition)*
    - identifiable person = *who can be identified, directly or indirectly*
  - Pseudonymised (or coded) data = personal data
    - pseudonymised data = personal data replaced by a unique code (identification remains possible)
      → use of a trusted third party recommended
When should you contact the CNPD? (3/3)

- NOT for research project with no personal data / anonymous data
  - Anonymous data = data irreversibly anonymised (strict definition)
    - impossible (for researcher or any other person) to identify an individual

- In case of doubt \(\rightarrow\) contact CNPD
What should you ask for? (1/2)

- **Prior authorisation**

  **When?**
  - Further processing / secondary use of data for historical, statistical or scientific purpose, regardless of nature of data (≠ direct collection of data from data subject)
  - Genetic data are processed

  **How?** By simple letter – no predefined form
  → letter must contained information explained on our website

  **What?** Legal review of the research project by the CNPD
  → Wait for approval of the CNPD to begin the project
What should you ask for? (2/2)

- **Prior notification**

  **When?** Direct collection of personal data (except genetic data)

  **How?** Notification form

  **What?** Administrative formality (no legal review)
Who should ask it?

- the “data controller”

  - Data controller = “determines the purposes and means of the processing of personal data”
    
    • Purposes = “why?”
    
    • Means = “how?”
What are your duties?

- **Purpose principle**
  - data collected for specified purpose(s) and not "re-used"
  - if further processing, « compatibility of purposes »

- **Legitimacy principle**
  - Need to legitimize the research project on the restrictive criterions as provided for in the law
    → ex. consent of the data subject

- **Necessity and proportionnality principles**
  - « Need to have, not nice to have »

- **Limited data retention period** → deletion of data

- **Confidentiality and security measures**
What are the data subjects’ rights?

- **Information of data subject**
  - Identity of data controller (mandatory)
  - Purposes of the research project (mandatory)
  - Categories of data + categories of recipients + existence of right of access and rectification

- Refusal to participate → no ulterior contact

- Consent withdrawal during the research project → Erasure of data

- **Right of access**
  - Copies of data
  - Origin of data
  - Rectification, deletion or blocking of data if inaccurate or incomplete
In the future:
General Data Protection Regulation

- Duties of the researcher and data subjects’ rights = similar
- Lighter administrative steps, but accountability
Conclusion

- If research project with personal data:
  - take into account data protection issues at the beginning of the study
    - Authorization / notification
    - Your duties and data subject’s rights
  - contact the CNPD for questions
Thank you for your attention!

Questions?

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