

ROLE CARD

Researcher

Researchers to be involved are, for instance:

- An applicant in a project in which awareness of data protection issues needs to be documented
- A PhD student who takes daily decisions about the management of personal data
- A Master's student who is developing their research plan

Why we need you in the team:

- Building data protection in the research design requires the active involvement of the researchers
- To help to design the dataflow and evolve your data management plan
- To identify good practices to deal with personal data in your research field
- To analyse how the proposed technical and organizational solutions fit into your research process

Dataminimization

IT security goals:

Confidentiality
Integrity
Availability

Data privacy goals:

Unlinkability
Intervenability
Transparency



- Do I target the impact on people’s fundamental rights, freedoms, and interests and not only on the risks to my organization?
- Is it easy for people to exercise their rights to access, rectification, erasure, etc.?
- Among the data collected, which data are personal data? Which ones are sensitive data?
- Did I identify all of the purposes of processing data in the data life cycle? Are all purposes compatible with the initial purpose?
- Are there data items I could remove (or hide) without compromising the purpose of the process?
- How long do I need to store the data? For which purpose(s)? Are there discipline-specific criteria for storage periods?
- Are discipline-specific good practices used for the analysis?



ROLE CARD

Ethics know-how

In a research project the ethics know-how can be found in:

- A member of an ethics board of the faculty (or the faculties involved for multidisciplinary research)
- An independent ethics advisor (often mandatory in European projects)
- An experienced researcher who is aware of good practices in their field

Why we need you in the team:

- To take into account the interests of Parkinson's patients participating in the project research
- To encourage participants in the Data Protection Impact Assessment (DPIA) to take responsibility for bringing solutions further.
- To provide information about the ethics assessment in the faculty
- To stimulate a privacy culture and the documentation of good practices and solutions
- To stimulate aligning data management, ethics and data protection in research projects

Dataminimization

IT security goals:

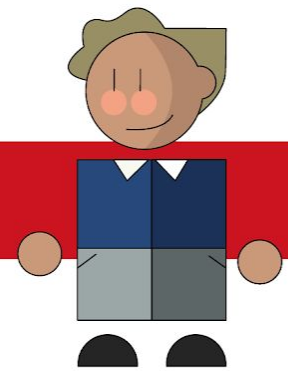
Confidentiality
Integrity
Availability

Data privacy goals:

Unlinkability
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Transparency



- Can people expect this processing of personal data to happen, even if they do not read the information the researcher provided?
- What if the collected data are reused for a study different from the research project?
- In case the researcher defers informing people, how do you advise to deal with the ethical dilemma?
- Concerning consent, has it been freely given by the participants? How does the researcher document it?



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Security/IT expert

Information security/IT experts are for example

- The Security Officer of the University.
- A data steward who can advise in detail what kinds of data are processed and how they can be shared.
- A data manager, who knows where to get expertise on security or a security expert who knows about data management.

Why we need you in the team:

- To help to visualise the dataflow
- To identify possible risks related to the use of software, apps, external devices, etc.
- To identify possible technical solutions
- To analyse how technical solutions may fit into your organization
- To give advice on good practices and bring experiences from an IT perspective

Dataminimization

IT security goals:

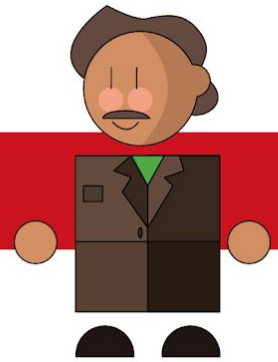
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- Do you have a procedure to perform identification, analysis and evaluation of the information security risks possibly affecting personal data and the IT systems supporting their processing?
- Do you target the impact on people’s fundamental rights, freedoms and interests and not only on the risks to the organization?
- Do you take into consideration the nature, scope, context and purposes of processing when assessing the risks?
- Do you manage your system vulnerabilities and threats to your data and systems?
- Do you systematically review and update the security measures in relation to the context of the processing and the risks?
- How can you ensure that data is only used for their defined purposes?
- Are there data items you could remove (or mask/hide) without compromising the purpose of the process?
- Do your tools allow for the updating/correcting of data where necessary



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Legal know-how

Legal know-how can be found in the role of, for instance:

- A lawyer
- A consultant who can find trusted relevant information

Why we need you in the team:

- To keep an eye on the rights of the data subject and not only on the risks for the institution
- To give advice on the procedure and criteria for derogations for research
- To give advice on the criteria under which a Data Protection Impact Assessment (DPIA) is mandatory
- To stimulate documentation of good practices and solutions
- To stimulate the aligning of data management, ethics and data protection in research projects

Dataminimization

IT security goals:

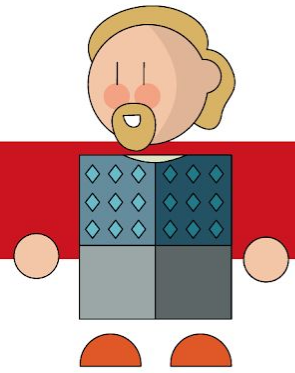
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- Can people expect this kind of processing to happen, even if they do not read the information provided?
- How can you ensure that data is only used for their defined purposes?
- Has the researcher transferred from the research participants to third-party data? If so, did she have the consent from the participants? Did she inform them about the sharing of their data and the purpose of re-use?
- Do the data subjects receive clear and complete information?
- In case an algorithm is used for automated decision making, which kind of information should the insurance company provide to its clients?



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Data subject

A data subject is (in this case):

- A Parkinson's patient participating in the research project
- A client or prospective client of the insurance company

Why we need you in the team:

- To discuss your concerns about the processing of your personal data for research purposes or about their processing to test an application relating to the health condition.

Dataminimization

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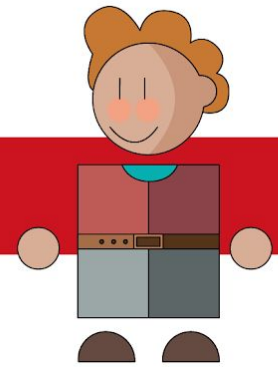
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- Have you received appropriate information concerning the collection, use, storage or transfer of your personal data?
- In case you gave your consent, how can you revoke it?
- What if the collected data are reused for a study different from the initial research project? Or are shared with a third party?



ROLE CARD

Data manager of the archive

Why do we need you in the team?

- There is a need to clarify responsibilities to harmonize data sharing of research data in this field
- As data manager of a domain specific archive you know how important documented measures and certification, like the CoreTrustSeal for data repositories (<https://www.coretrustseal.org/about/>), can be.
- You may also know other examples and good practices, like initiatives for discipline specific codes of conduct, to be transparent about possibilities and shared responsibilities for data sharing.
- You know what are the needs of researchers to assess if specific protection measures will limit the integrity and re-usability of the research data. And maybe you can assess the costs of data re-usability and help researchers to assess other options to make the data FAIR, if the data cannot be shared.

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- Is there a risk that the data could be reused for other purposes (function creep) that do not fit with the consent of the participants?
- How can you ensure that data is only used for their defined purposes?
- Are there data items you could remove (or mask/hide) without compromising the purpose of the process?
- Do your tools allow for the updating/correcting of data where necessary?
- In case you want to make available/re-use data for scientific research, statistical or historical purposes, what safeguards do you apply to protect the individuals concerned?
- How do you clarify the responsibility of the researcher/institution that archives the data and your responsibility? How do you communicate the essence of those arrangements with the data subject?