

Data Protection Impact Assessment roleplay

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Builds upon two use cases from the DELAD Initiative

LREC 2020 paper: Corpora of Disordered Speech in the Light of the GDPR



Needed for research purposes:

- appropriate safeguards which ensure technical and organisational measures
- legal ground and compliance with data protection principles

- open question: who is controller in research collaboration...shared responsibilities; GDPR says: clarify & be transparent

- derogations for research not harmonized, but still need to be in keeping with the essence of data protection and discipline-specific good practices

How to find appropriate measures in innovative use cases, that want to share sensitive data?

Fraunhofer publica:
The Data Protection Impact Assessment
According to Article 35 GDPR
A Practitioner's Manual

<http://publica.fraunhofer.de/documents/N-590015.html>

Why DPIA in research:

- high risks (derogations, open science)
- shared responsibilities
- German method (protection goals, standard data protection model, multistakeholder approach)



What could the DPIA method bring for CDS data? -applied on use cases of the ELRA article

Use Case 1:

Keywords: clinical datasets, different sources, multidisciplinary effort in collection, sensitive health data, secure system, ethical assessment, transparency on data sharing with vulnerable data subjects

Use Case 2:

Keywords: archival recordings, metadata of hearing impaired children, legal ground, further processing, sensitive nature of metadata, balancing assessment, stored at TLA

- design appropriate measures
- the concept of a reference DPIA

1. design and awareness for importance of collaboration (legal, IT, researcher, data subjects, third parties)
 2. documented measures in report is also way to consult & get green light of the authority
- joint responsibilities: promote documentation: develop (ethical) standards.

A holistic multistakeholder approach: Example Parkinson Case

<https://youtu.be/H3WFEfieLm4>



additional issues:

- responsibilities of researcher as developer
- algorithmic transparency
- ethics by design
- understand diverse forms of regulation: other legal perspectives (IP, health apps)



The DPIA Method

It is a **multi-stakeholders** approach that provides a **structured** way of thinking about risks and protection measures.

The risk assessment is based on **protection goals**.





Protect the data from unauthorized person.

The data are intact, complete, and up-to-date.

Transparency of the entire data processing operation with the participants and with the authorities.



Data shall be processed only for the purpose for which they were collected.

Guarantee the rights of the participant at any time.

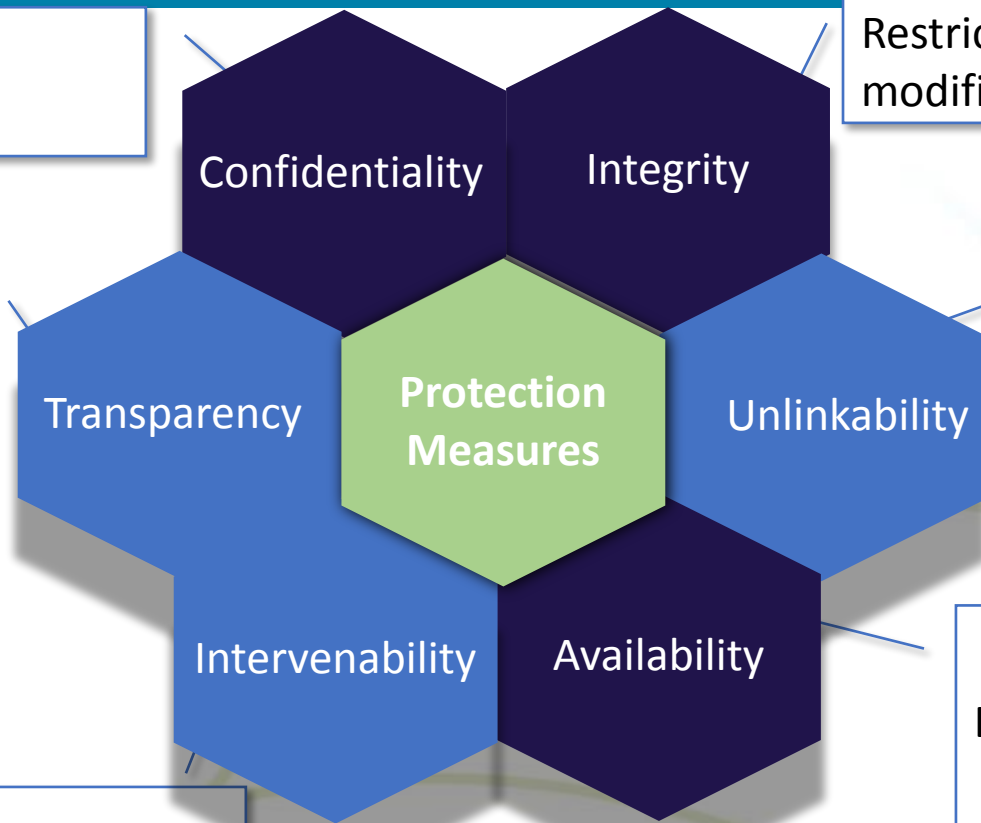
Data must be available during the project and to authorised parties.



A secure authentication system.

- Informed consent for the participants
- Documented discipline-specific good practices
- Information about rights of data subjects

A Single Point of Contact (SPoC) for the rights of the data subjects.



Restriction of writing and modification permissions.

Pseudonyms, anonymisation techniques.

Data backups

Conclusion and way forward



1. training next generation with holistic approach
2. explore integration of institutional responsibility and discipline specific expertise
3. develop transparency & standards on shared responsibilities in research context

Programme

10.00-10.15 Welcome and presentation on the DPIA in research and education

10.15-10.25 Discussion on expectations

Break to get into your role

10.30-11.20 The roleplay Data Protection Impact Assessment (step 2)

Part 1 (research general) 10.30-10.50

Part 2 (building an app with insurance company OR archiving at ACE)

10.55-11.20

11:20-11.30 Break

11.30-12.00 Evaluation (step 3)

Questions?

Tips for getting into your role

1. Build your role (who is this person, old, young, interests, dog?)
2. Go with the flow
3. Enjoy

Tips to get the discussion flowing:

1. ask open questions and/or ask a question to a specific other role.
2. write down ideas to elaborate later

Appoint someone to present the main outcomes in the (link) report

What did you experience and what should DELAD do next?