

DELAD: How to share and access sensitive datasets with language and speech disorders via CLARIN

Workshop 22-23 Sep. 2022



UNIVERSITY OF HELSINKI



CLST | Centre for Language and Speech Technology
Radboud University



CONTRIBUTION TO CLARIN GOALS

DELAD stands for Database Enterprise for Language And speech Disorders, and is also Swedish for SHARED. DELAD is an initiative to share corpora of speech of individuals with communication disorders (CSD) among researchers. We do this in a GDPR compliant way and at secure repositories in the [CLARIN](#) infrastructure.

These were the topics of the workshop:

- Recent developments at ACE / DELAD for support of sharing CDS.
- Sharing clinical data: Sharing clinical data via hospitals.
- The impact of the Data Governance Act & Data Altruism.
- Follow up on voice pseudonymisation.

ORGANISERS

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PARTICIPANTS & EXPERTISE

30 participants from 10 countries

Covering various expertise:

- Researchers in language disorders
- Incl. data collection projects
- Infrastructure specialists
- IPR/GDPR specialists

SOME RESULTS & RECOMMENDATIONS

Relation of DELAD & CLARIN:

- DELAD as interest group within CLARIN focusing on practical issues on sharing CDS.
- CLARIN is the Data Trust, to provide the data fence around CDS.
- DELAD organises regular workshops on issues around CDS in CLARIN-context.

IPR, GDPR & Ethics:

- Data Governance Act & Data Altruism will be further explored.

DELAD has published a number of interesting guidelines:

- Educational material: Roleplay & video on Data Protection Impact Assessment (DPIA) for sharing sensitive patient research data information:
<https://delad.ruhosting.nl/wordpress/dpia-role-play-with-video/>
- Guidelines, tips, examples for informed consent & storage of sensitive data:
<https://delad.ruhosting.nl/wordpress/guidelines-consent-storage/>
- Coming up: guidelines on annotation of recordings of disordered speech.

DELAD & Data centres for CDS:

- MPI/TLA as a CLARIN B centre, provides the archive for CDS.
- DELAD and TLA closely collaborate with TalkBank / Clinical Banks at CMU.
- Special provisions at TalkBank for EU-based sensitive data.



FOLLOW UP

For more information about the workshop visit:

<https://delad.ruhosting.nl/wordpress/delad-workshop-2022/>

<https://delad.ruhosting.nl/>



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