

File: 2023_Health-RI_DANS-UC-MRI

Health-RI course: FAIR data stewardship basics
Module: Publishing and archiving data
03/07/2023 Utrecht, The Netherlands
[cc by 4.0](https://creativecommons.org/licenses/by/4.0/) | DOI: 10.5281/zenodo.8101838
Kim Ferguson & Cees Hof
Data Archiving and Networked Services (DANS-KNAW)



Hands-on exercise

Timeline:

- 40 minutes, split into two halves (20 min per use case)
- recap in the final 10 minutes of the session

Tools:

- flipcharts
- sticky notes
- your laptops (maybe re3data or the GDPR decision tree?)
- the use cases & the “researchers in need”

Prompts to consider for both use cases:

- How much data is there?
- Would one repository be appropriate for all types of data?
- For how long should the data/output be stored?
- Who should be able to find and re-use the data?
- How much budget do you have for preservation?
- What should be preserved and what not?
- Is this data considered sensitive data?
- Are there funder requirements or project requirements (DMP)?
- Any software and/or code involved?
- What is the publication strategy?
- How FAIR is the data now?

Use Case 1-a: Project “MRI research brain damage” (fictional)

Project coordinator: Prof. dr. Erik Swaab, Maastricht UMC+
Duration project: January 2018 – December 2020.

100 patients with light to severe brain damage, caused by cerebral haemorrhage, were monitored during their first 6 months of their recovery.

Measurements included:

- MRI imaging on a weekly base
- Continuous measurements of general physical conditions (full blood picture, etc.)
- Weekly video interviews, monitoring the patient’s speech and facial expressions
- Information on family history in relation to cardiovascular diseases

MRI data were all processed using proprietary software from the companies providing the MRI scanners.

The results were captured in a major publication in The Lancet.

All patients have signed an informed consent declaration considering the use of their personal data for research purposes.