

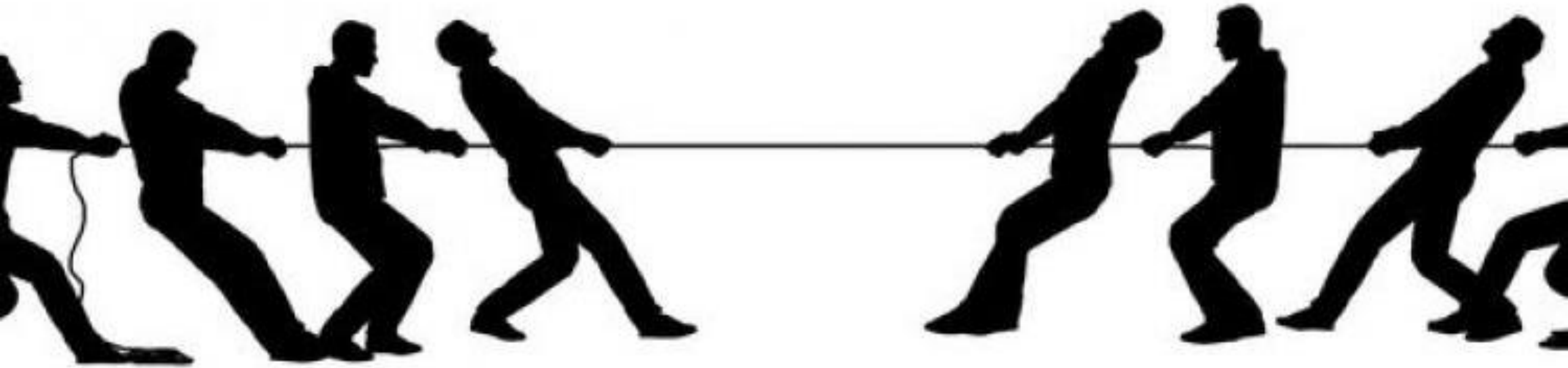
Issuing a Data User Agreement example from the Donders Repository

Robert Oostenveld

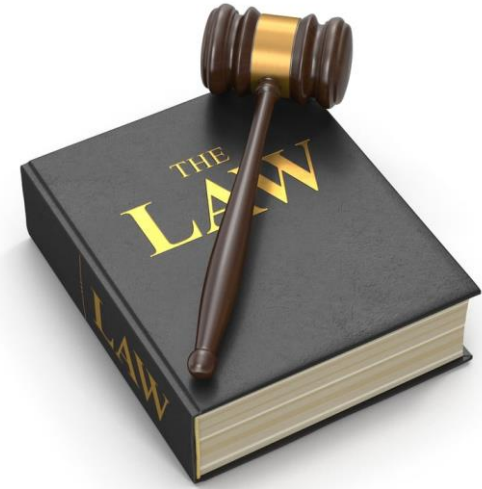
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Open data versus privacy



Personal Data



Personal data

Name, address, date of birth

Special personal data = “bijzondere persoonsgegevens”

Race

Religion or beliefs

Health

Sexual activities

Political preference, membership of a union

Criminal record

Indirect personal data – identifies someone when linked to another database

Fingerprint, DNA, facial details

Anatomical MRI

Specific pattern of answers on a questionnaire or interview

Personal data

name

address

date of birth

phone number

license plate number

...



Crime Scene Investigation

<http://www.abc.net.au/news/2017-09-19/csi/8960590>

This is the information the police will first look for on the crime scene. In case this cannot be found, CSI is called in.



Biometric data

facial details

dental record

fingerprint

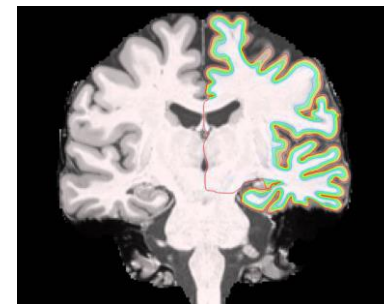
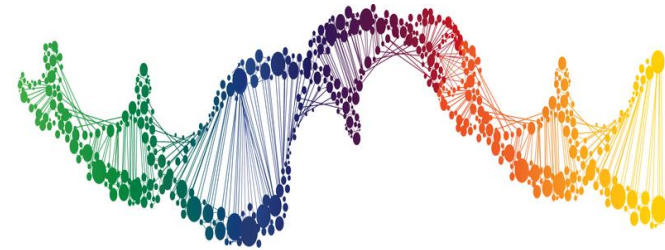
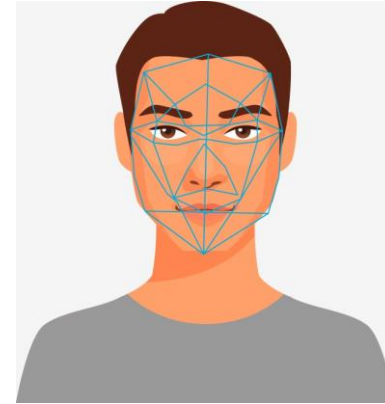
genetics

cortical folding pattern

clinical data

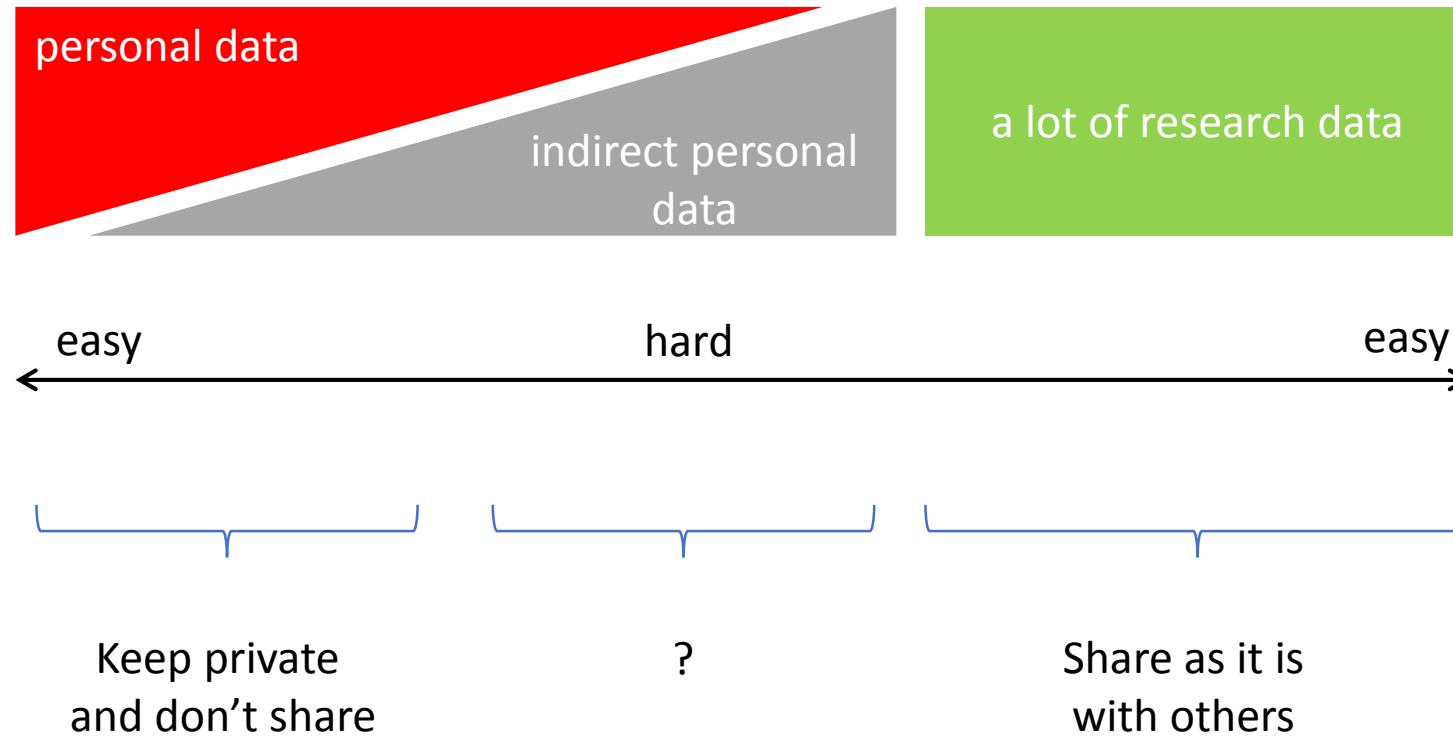
gait/movement pattern

...



These are identifying in case they are sufficiently unique and stable over time.

Gradient between personal and research data



Research data can be “indirect personal data”

Biometric data

- ... is identifying in case they are sufficiently unique and stable over time
- ... identifies someone when linked to another database

How to deal with this

- Pseudonomization , i.e. use code instead of name (not sufficient)
- Deidentification, i.e. modify/blur the data (potentially not sufficient)
- Implement legal constraints

Legal constraints

A background image showing two hands shaking in a firm grip. The hand on the left is wearing a grey sweater, and the hand on the right is wearing a blue and white striped shirt. The background is a bright, out-of-focus indoor setting.

Contract between the researcher

- ... and the funding agency
- ... and the ethics committee
- ... and the participants/patients
- ... and the publisher
- ... and the recipient of the data upon sharing*

DUAs to select from when researches deposit in the Donders Repository

See <https://data.donders.ru.nl/doc/dua/> for full overview

RU-DI-HD-1.0 potentially identifiable data

RU-DI-NH-1.0 non-human or non-identifiable human data

ODC-BY-1.0	OpenDataCommons Attribution License		
ODC-ODbL-1.0	OpenDataCommons Open Database License		
ODC-PDDL-1.0	OpenDataCommons Public Domain Dedication and License		
CC0-1.0	CreativeCommons Zero 1.0 Public Domain	GPL-2.0	GNU General Public License v2.0
CC-BY-4.0	CreativeCommons Attribution 4.0 International	GPL-3.0	GNU General Public License v3.0
CC-BY-ND-4.0	CreativeCommons Attribution-NoDerivs 4.0 International	LGPL-3.0	GNU Lesser General Public License v3.0
CC-BY-SA-4.0	CreativeCommons Attribution-ShareAlike 4.0 International	APACHE-2.0	Apache License 2.0
CC-BY-NC-4.0	CreativeCommons Attribution-NonCommercial 4.0 International	ARTISTIC-2.0	Artistic License 2.0
CC-BY-NC-ND-4.0	CreativeCommons Attribution-NonCommercial-NoDerivs 4.0 International	BSD	BSD 2-clause "Simplified" License
CC-BY-NC-SA-4.0	CreativeCommons Attribution-NonCommercial-ShareAlike 4.0 International	EPL-1.0	Eclipse Public License 1.0
		MIT	MIT License
		MPL-2.0	Mozilla Public License 2.0
		ISC	ISC License
		PD	Public Domain

Comparing two agreements

CC0 - Public Domain

No copyright.

*The person who associated a work with this deed has dedicated the work to the public domain by **waiving all of his or her rights** to the work worldwide under copyright law, including all related and neighboring rights, to the extent allowed by law.*

*You can **copy, modify, distribute and perform the work**, even for commercial purposes, all without asking permission.*

Data use agreement for identifiable human data

*I will comply with all relevant **rules and regulations** imposed by my institution and my government.*

*I will not attempt to establish the identity of or attempt to contact any of the included human subjects. I will **not link this data** to any other database in a way that could provide identifying information*

*I will **not redistribute** or share the data with others, including individuals in my research group, unless they have independently applied and been granted access to this data.*

I will acknowledge the use of the data and data derived from the data when publicly presenting ...

*Failure to abide by these guidelines will result in **termination of my privileges** to access to these data.*

<https://creativecommons.org/publicdomain/zero/1.0/>

<https://data.donders.ru.nl/doc/dua/>

General elements of Data Use Agreement

1. If applicable, the agreement must specify how to deal with **subject confidentiality** issues.
2. If applicable, it must specify how to deal with ethical issues regarding **animal research**.
3. It must specify the requirement to **abide to all laws and regulations** (both in the jurisdiction of the data recipient and in the Netherlands)
4. It should specify whether there are **restrictions** to the use of the data.
5. It should specify whether and how original and derived data can be **redistributed** and/or shared.
6. It should specify the **liability** for data and derived data that is redistributed.
7. It should specify whether and how **credits and acknowledgements** are to be handled.
8. It may specify specific situations under which the agreement is **terminated**.

Consequences of the DUA for the re-users of data from Donders Repository

When *not* redistributable

- Users have to register (e.g. ORCID, including email address)

- Users have to explicitly agree with DUA (“click through”)

When redistributable

- Registration by users is not needed

- Explicit agreement is not needed

