



Aalto University

GDPR – PRACTICAL IMPLICATIONS FOR RESEARCHERS

Examples and solutions from brain research

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Personal data handling and sharing: Do you need all the data?

- **GDPR: a great opportunity to reflect on data collection**
- **As researchers we are allowed to handle personal data, but are they needed to answer our research questions?**
- **Ask yourself:**
 1. Which bits are **direct/indirect identifiers** of the data subject?
 2. Do I **need to store them** after data collection is over?

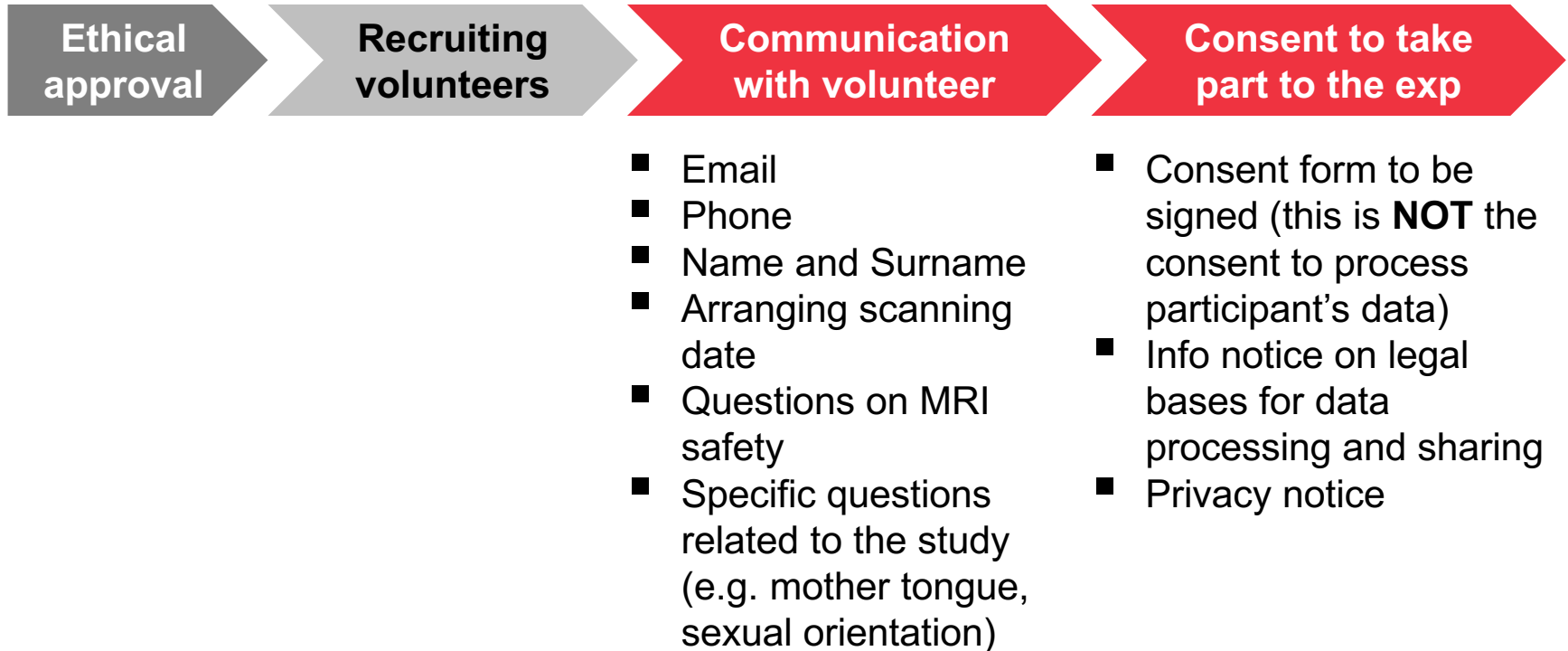
Goal: Remove all direct identifiers so that data can be *”As open as possible, as closed as necessary”* (EU Guidelines on FAIR data management in Horizon 2020)

For each collected data type, see if it is a direct/indirect identifier

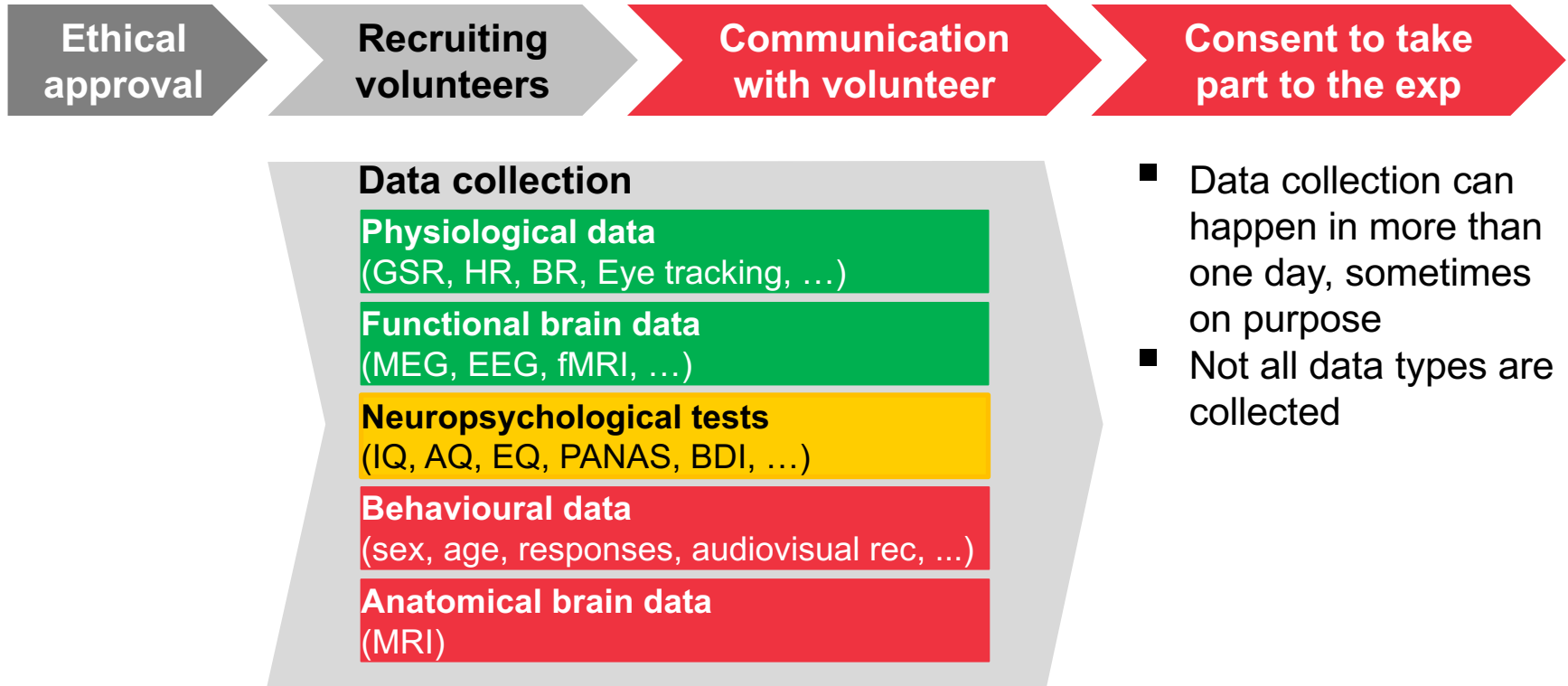
- See full table at: <http://www.fsd.uta.fi/aineistonhallinta/en/anonymisation-and-identifiers.html>
- **Not all data types are listed:** discuss with your peers and follow best practices in your field

Identifier type	Direct identifier	Strong indirect identifier	Indirect identifier	Anonymisation method
Personal identification number	x			Remove
Full name	x			Remove/Change
Email address	x	x		Remove
Phone number		x		Remove
Postal code			x	Remove/Categorise
District/part of town			x	Categorise
Municipality of residence			x	Categorise
Region			x	(Categorise)
Major region			x	
Municipality type			x	
Audio file	x			Remove
Video file displaying person(s)	x			Remove
Photograph of person(s)	x			Remove

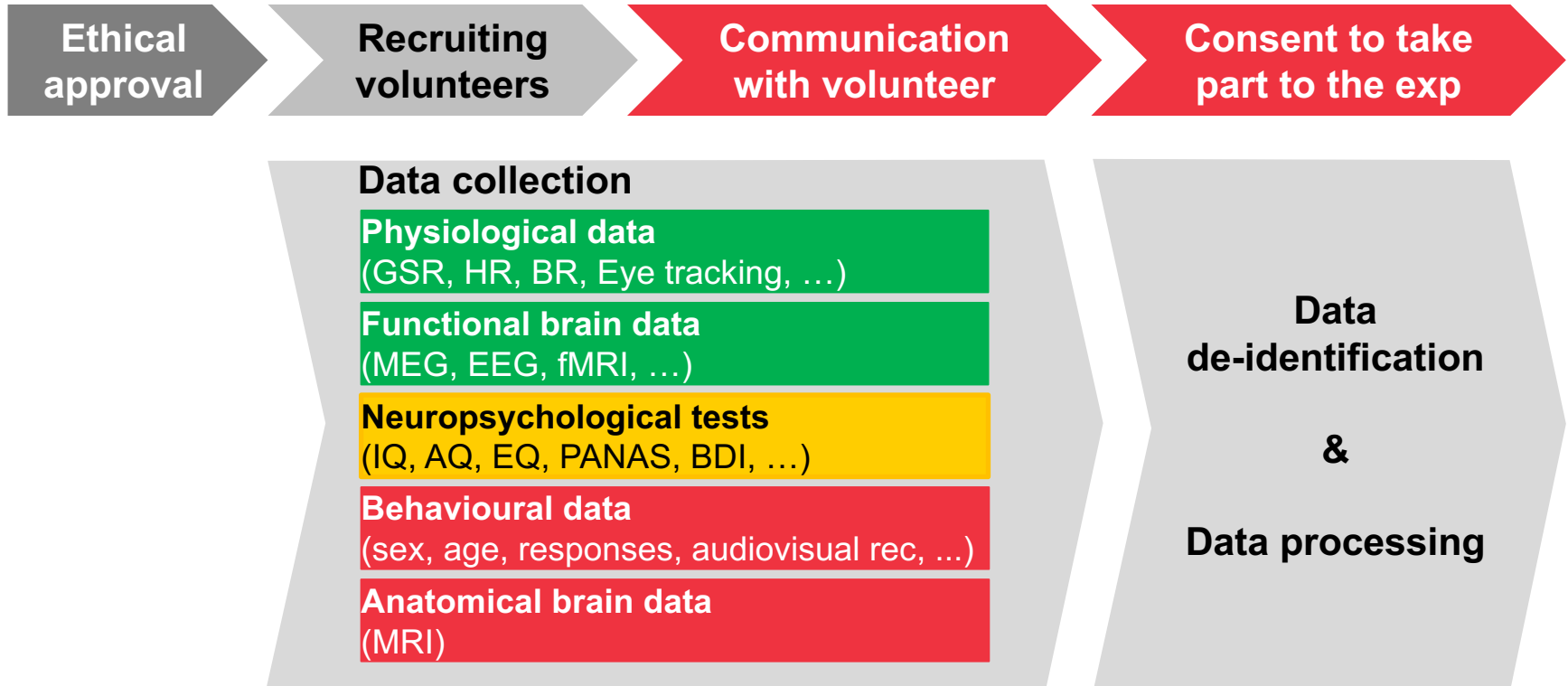
Example from brain research



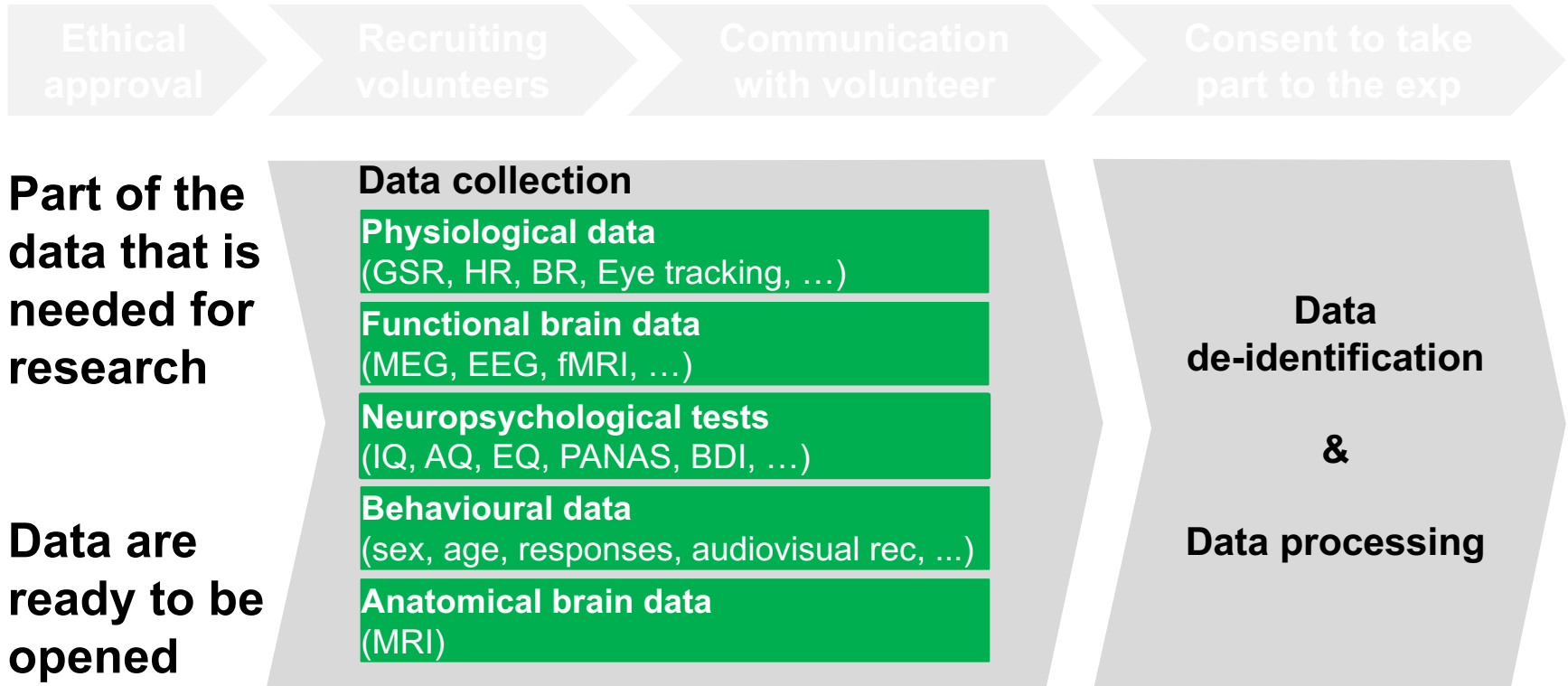
Example from brain research



Example from brain research



Data de-identification at step zero



However, consider each specific case

- **Data de-identification sometimes is not possible** (e.g. developing algorithms for face recognition)
- **Some individuals are more difficult to de-identify** (e.g. somebody with a rare disease, a celebrity with an unique skill, a psychopath who was in the news)
- It is a **trade off between the risks for the individual and the benefit for society**

You need to consider these implications before applying for ethical approval and discuss them with the ethical board.

Take home messages

- **GDPR will change the workflow of those who daily work with human data.** However, it is for the best of the subjects as well as the best for science (think of double blind trials)
- **Grant applications will reflect the changes introduced by GDPR.** Be ready to justify which personal data you must keep and which can be de-identified in your data management plan.
- **GDPR is a big step towards openness in research.** These changes will produce data that are ready to be opened from step zero.
- **Slides are on twitter @eglerean**