# Open Brain Consent GDPR edition

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# What are we doing? (IMO)

We shouldn't have to agree on everything when it comes to open data, personal data privacy, GDPR, infrastructure, and related things

#### But, we probably agree that:

- 1. Open data to underscore our research results and promote inclusivity is **generally desirable**
- 2. Achieving this, a standard form and process for open MRI data sharing, is **complicated**
- 3. We are **collaborating** to move towards this goal, and to make the process easier for all researchers

# Open data & privacy

From <a href="https://open-brain-consent.readthedocs.io">https://open-brain-consent.readthedocs.io</a>:

"for neuroimaging studies there is no commonly accepted version of a Consent form template which would allow for collected imaging data to be shared as openly as possible while providing adequate guarantees for subjects' privacy"

## Open Brain Consent



https://open-brainconsent.readthedocs.io

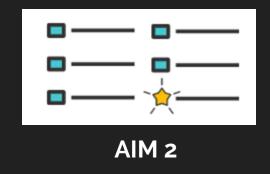
(from <u>Datalad</u>; first released in 2015)

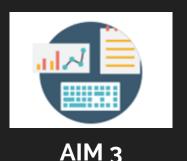
- 1. Informed consent templates
- 2. Multiple language translations
- 3. Anonymization tools
- 4. More...

## OHBM Hackathon 2019 - Rome

Open Brain Consent is great, but not yet suitable for use in the EU, where GDPR compliance is required. Let's update it!







DISTILL GDPR CONCEPTS

**TEMPLATES!** 

EDUCATIONAL CONTENT

### OHBM Hackathon 2019 - Rome

#### Outputs and links:

- 1. Project folder on Google Drive
- 2. Summary <u>description of project</u>
- 3. Summary doc for <u>Core GDPR concepts</u> related to brain imaging data
- 4. Communication: mattermost channel
- 5. Original hackathon project description

## Today and future view (IMO)

- 1. Today: use OBC and OHBM hackathon progress, learn from experience of today's participants, and **create a usable set of informed consent and DUA templates** for sharing clinical (and healthy volunteer) MRI data.
- 2. Future:
  - a. Improve templates as more use cases emerge
  - b. Generate decision tree to assist researchers
  - c. Update OBC with resources (e.g. anonymization; tutorials)
  - d. Generate educational material
  - e. Write-up *general* consensus on use of standard templates and processes