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# EU Cost Action GliMR - European multi-site data integration & large dataset creation for glioma diagnostics

Camille Maumet

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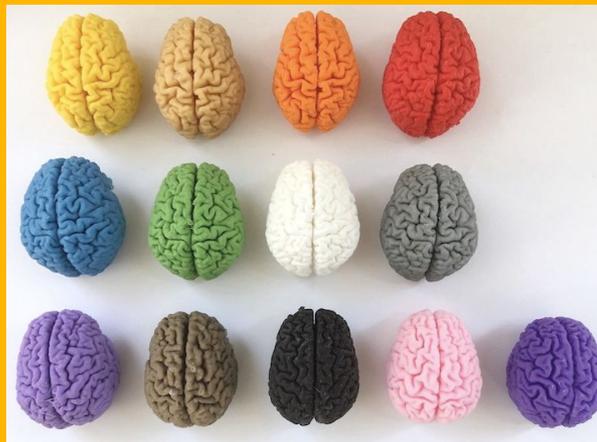
Submitted on 9 Apr 2021

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# EU Cost Action GliMR — European **multi-site data integration** & large dataset creation for glioma diagnostics



**Camille Maumet**

Univ Rennes, Inria, CNRS, Inserm



# Glioma MR Imaging 2.0

- Build a pan-European and multidisciplinary network of **international experts in glioma research, patient organisations, data scientists, and MR imaging scientists**
- Use **advanced MR imaging for improved decision making** in diagnosis, patient monitoring, and assessment of treatment response in clinical trials and clinical practice.



Esther Warnert



Radim Jancalek



Jan Petr



Vera Keil



Lydiane Hirschler



## WG1 - Advanced MRI biomarkers for glioma characterisation

Working Group 1 focusses on coordinating the identification and quantification of advanced MRI biomarkers for the application in the field of glioma.



Kyrre Emblem



Marion Smits



Fran Borovecki



## WG4 – Stakeholder relations

Working Group 4 ensures representation of all relevant stakeholders within GliMR and acts as liaison from GliMR to all relevant stakeholders.



## WG2 - Multi-site data integration

Working Group 2 coordinates multi-site data integration and enables the creation of large datasets in glioma diagnostics via the creation of common GDPR- and BIDS-compliant forms and data structures.



## WG5 – Dissemination

Working Group 5 disseminates the Action's goals and results in tailored manners to all relevant stakeholders.



## WG3 - Clinical translation

Working Group 3 focusses on fostering cross-border information exchange about past and current clinical trials and studies of glioma.



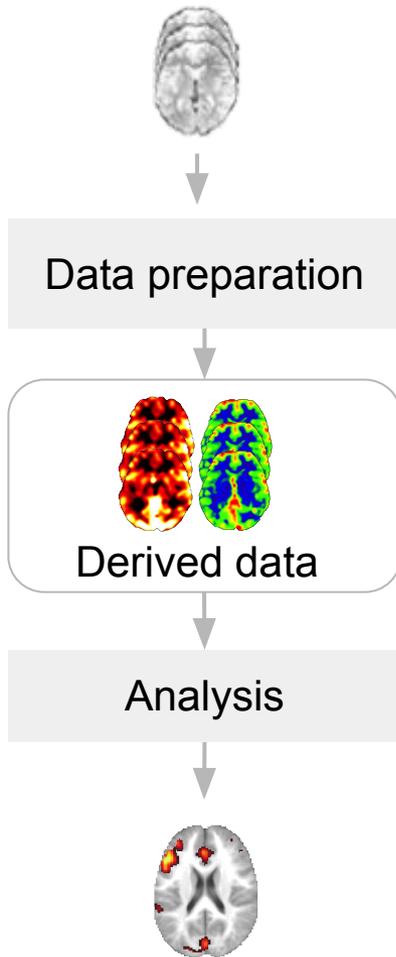
Patricia Clement



Joana Pinto



# Gliomas research in Europe



- **50,000 new cases** of gliomas per year in Europe

- **Low incidence** rate

>> Limited samples sizes

SCIENCE

## A Waste of 1,000 Research Papers

Decades of early research on the genetics of depression were built on nonexistent foundations. How did that happen?

ED YONG MAY 17, 2019



SEAN NEL / SHUTTERSTOCK

In 1996, a group of European researchers found that a certain gene, called *SLC6A4*, might influence a person's risk of depression.

It was a blockbuster discovery at the time. The team found that a less active version of the gene was more common among 454 people who had mood disorders than in 570 who did not. In theory, anyone who had this particular gene variant could be at higher risk for depression, and that finding, they said, might help in diagnosing such disorders, assessing suicidal behavior, or even

**Irreproducibility**

## Why are middle-aged marathon runners faster than twentysomethings?

According to new data from the running app Strava, runners in their 40s are streets ahead of younger rivals



▲ 'Middle-aged runners outperform runners in the 20s ...' Photograph: FatCamera/Getty

**A**ccording to data released by the running app Strava, middle-aged runners consistently average faster marathon times than their younger rivals, apparently defying the usual rules of athletic performance. Men in the 40-49 age bracket clock an average time of four hours and 17 minutes for a marathon, according to the recent figures. Women in the same age range typically come in at just under the five-hour mark.

Faster in their forties  
than twenties?

**Selection bias**

The New York Times

## *Many Facial-Recognition Systems Are Biased, Says U.S. Study*

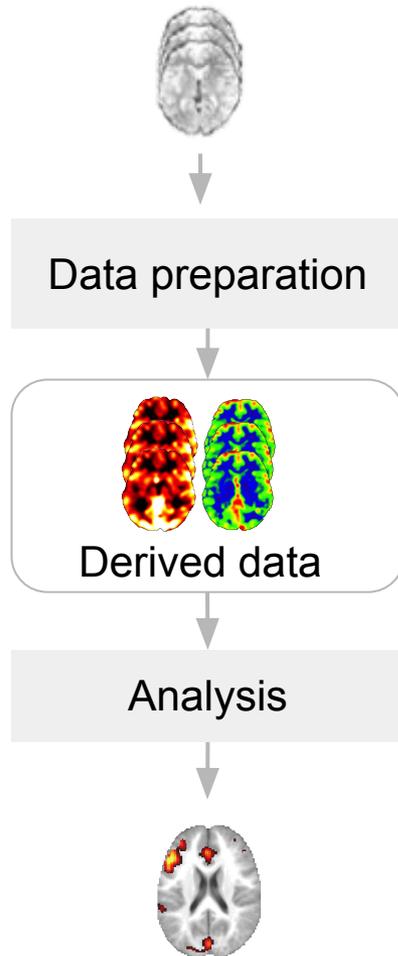
Algorithms falsely identified African-American and Asian faces 10 to 100 times more than Caucasian faces, researchers for the National Institute of Standards and Technology found.



Morning at Grand Central Terminal. Technology for facial recognition is frequently biased, a new study confirmed. Timothy A. Clary/Agence France-Presse — Getty Images

**Algorithmic injustice**

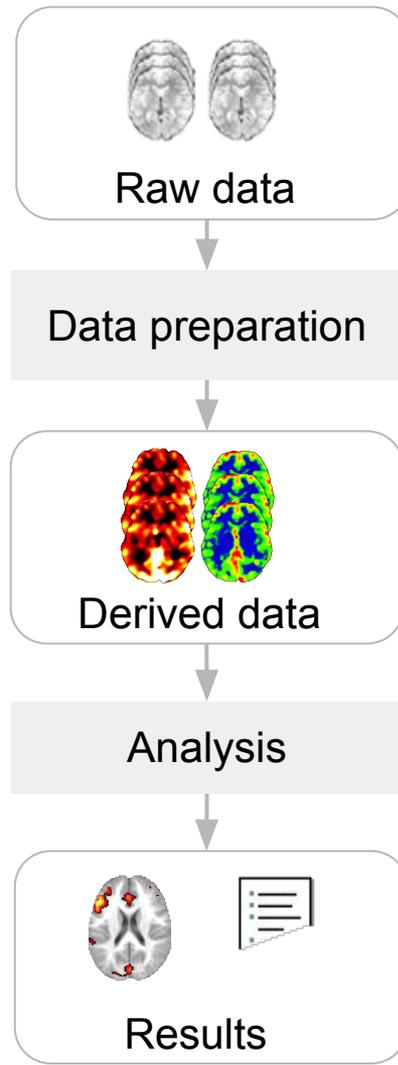
# A brain imaging study



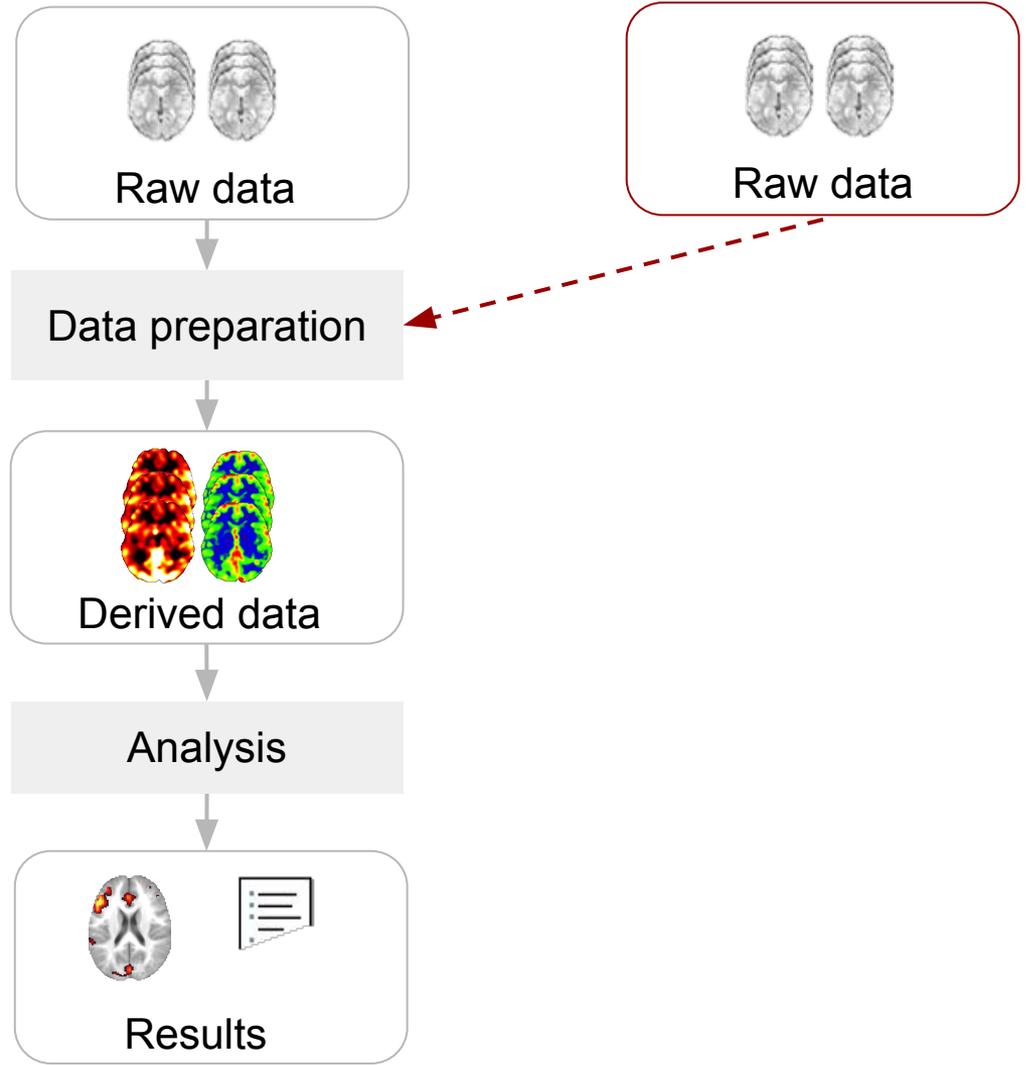
As a **community**, we need **bigger** & more **representative** samples

**Data** integration

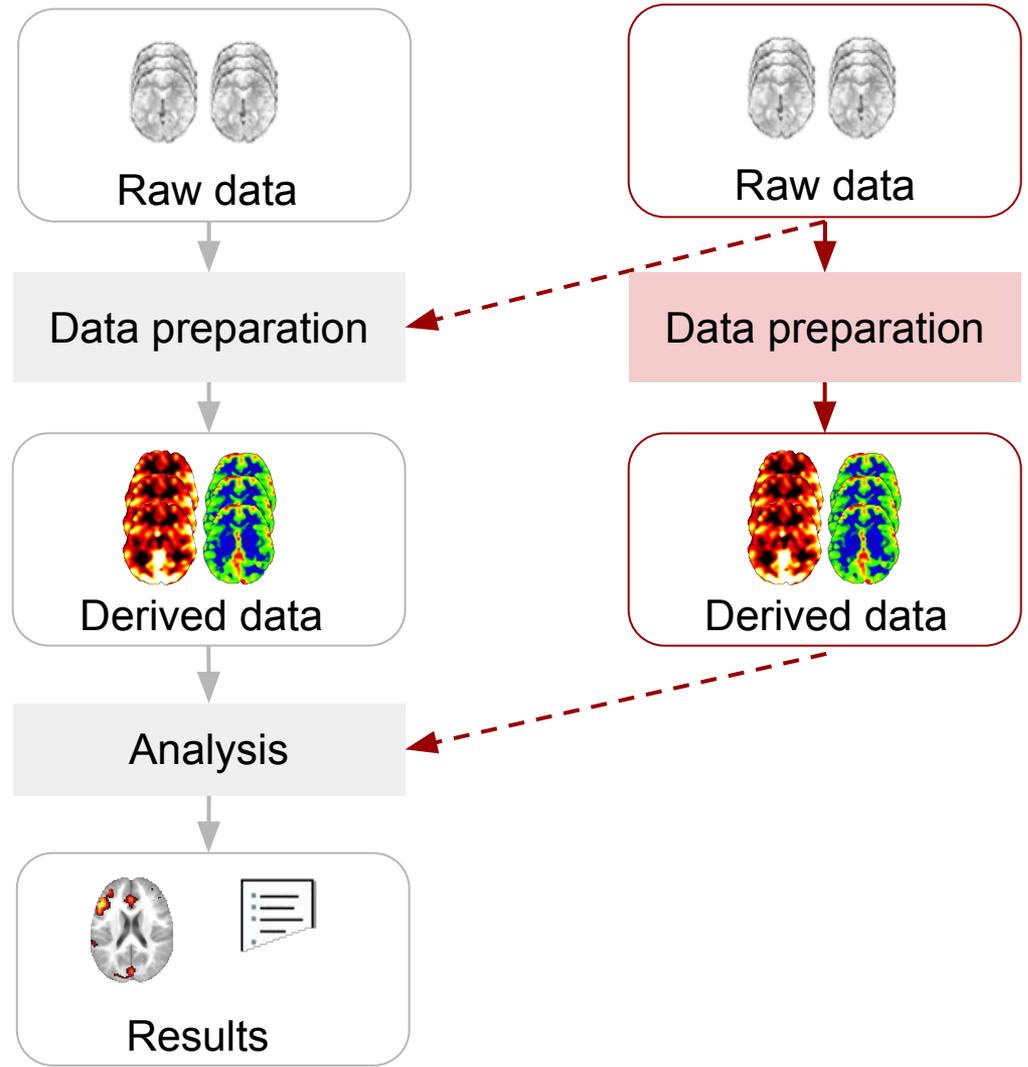
# Data integration



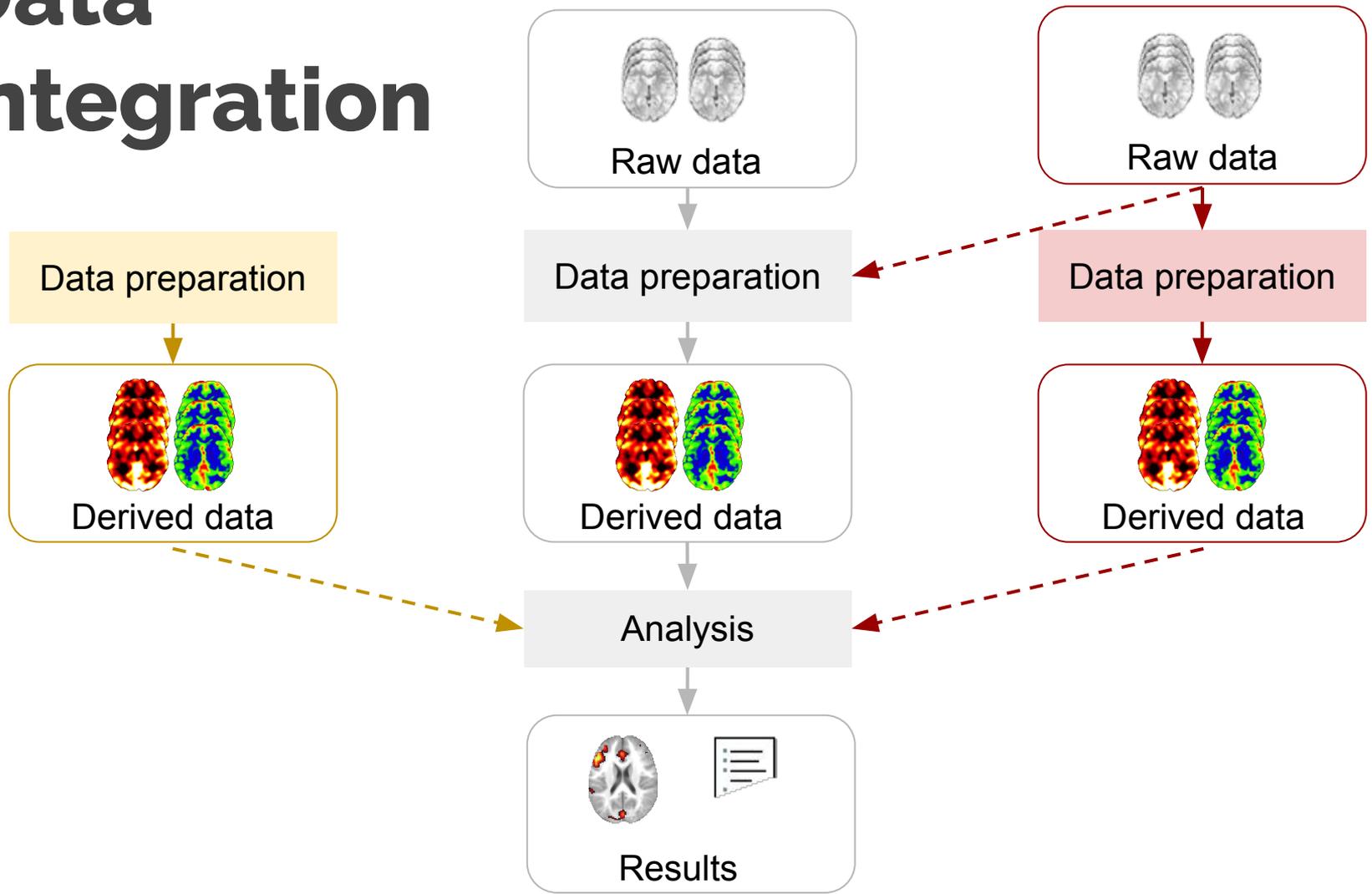
# Data integration



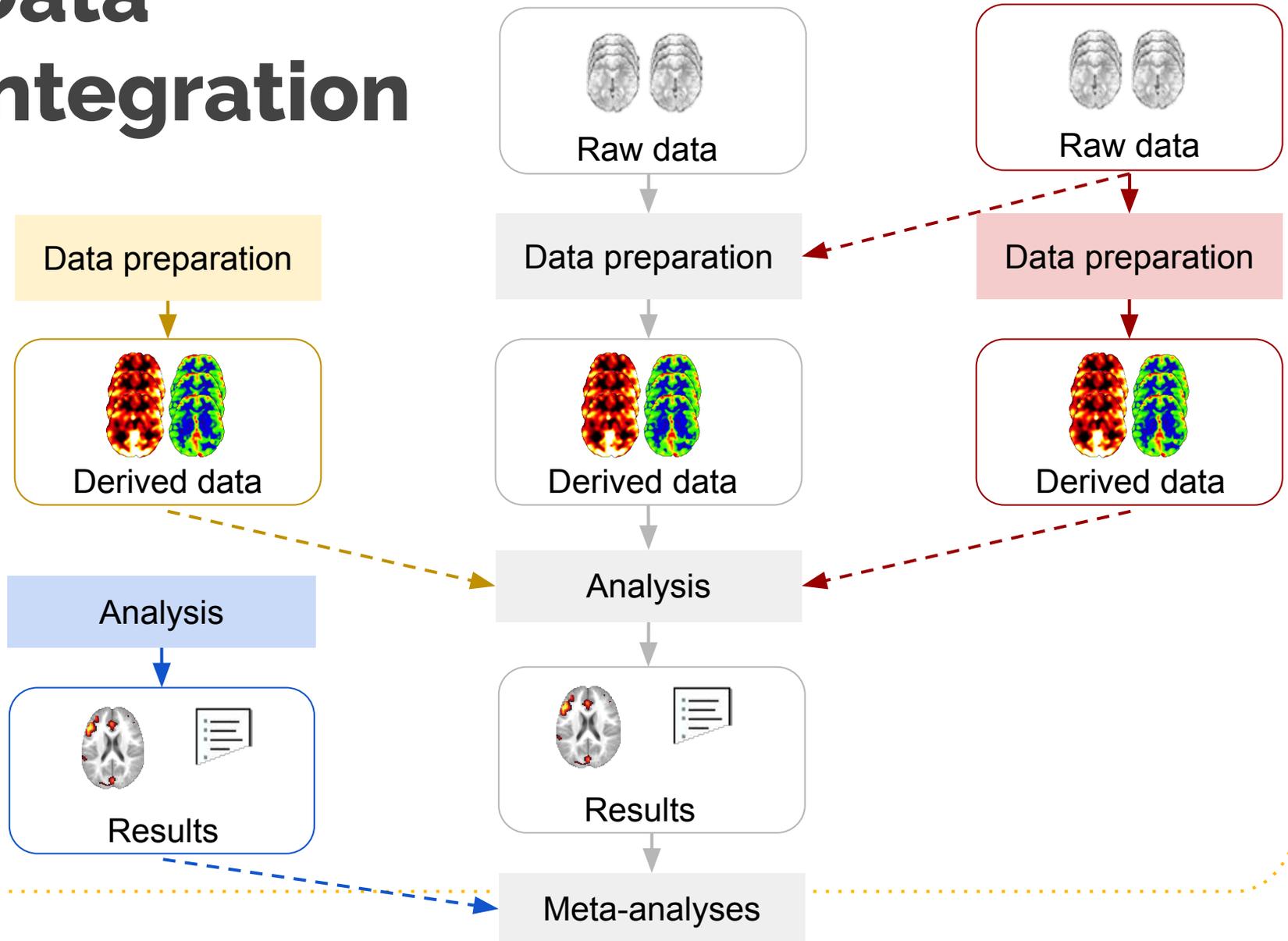
# Data integration



# Data integration



# Data integration



# GliMR WG2 **Multi-site data integration**

## WG2 - Multi-site data integration

Working Group 2 coordinates multi-site data integration and enables the creation of large datasets in glioma diagnostics via the creation of common GDPR- and BIDS-compliant forms and data structures.



Camille  
Maumet

Cyril  
Pernet



**Data Privacy**



**Data infrastructure**

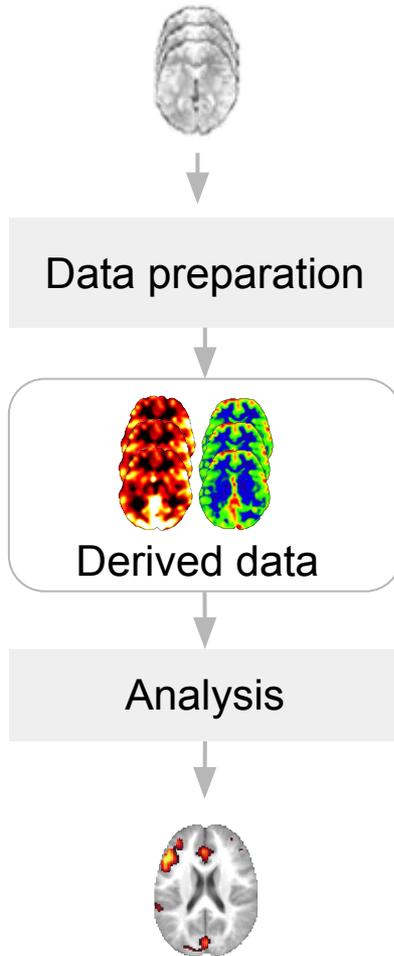


**Data portability**

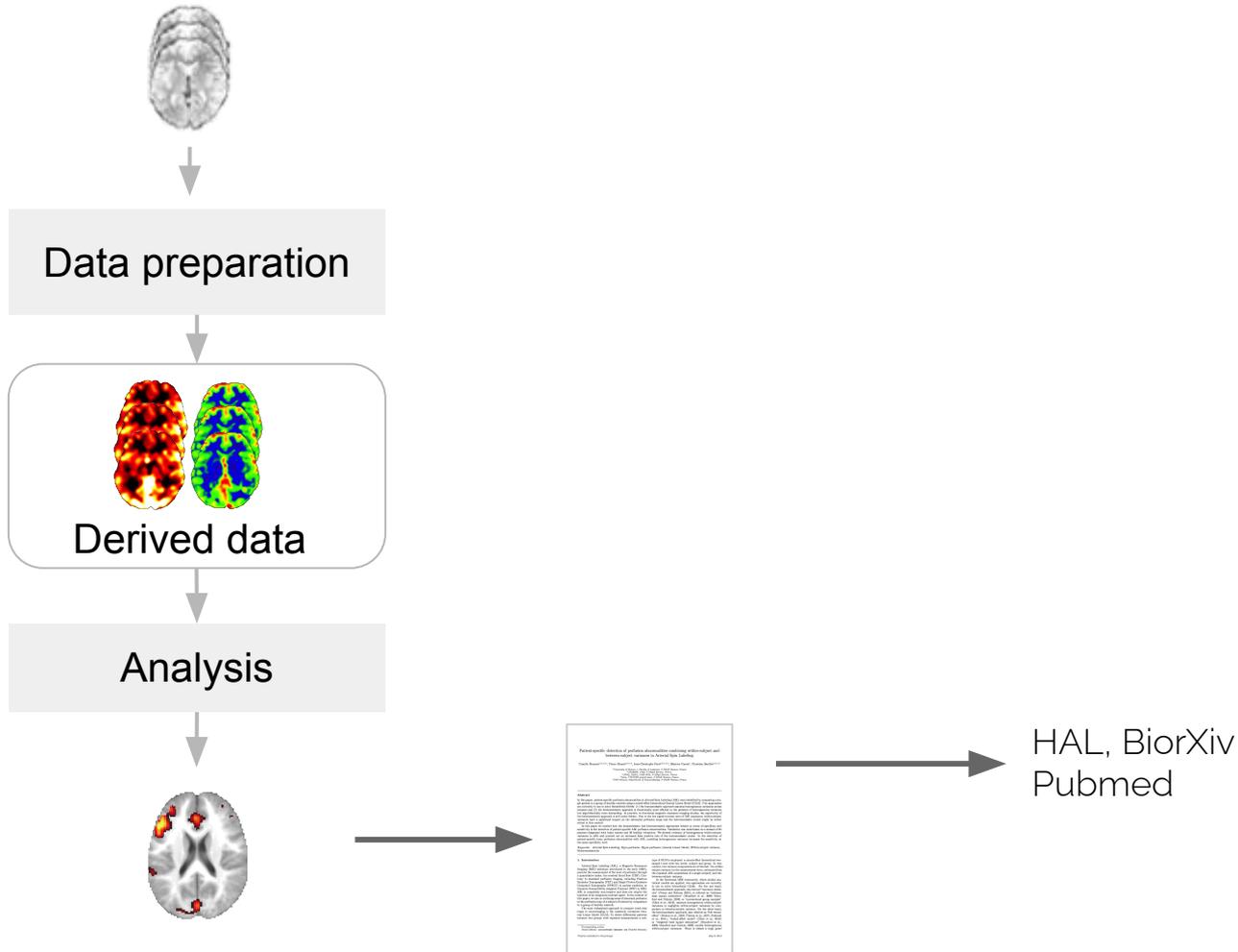
Image credits: "Privacy lock", "Transport map", "Mini bus"



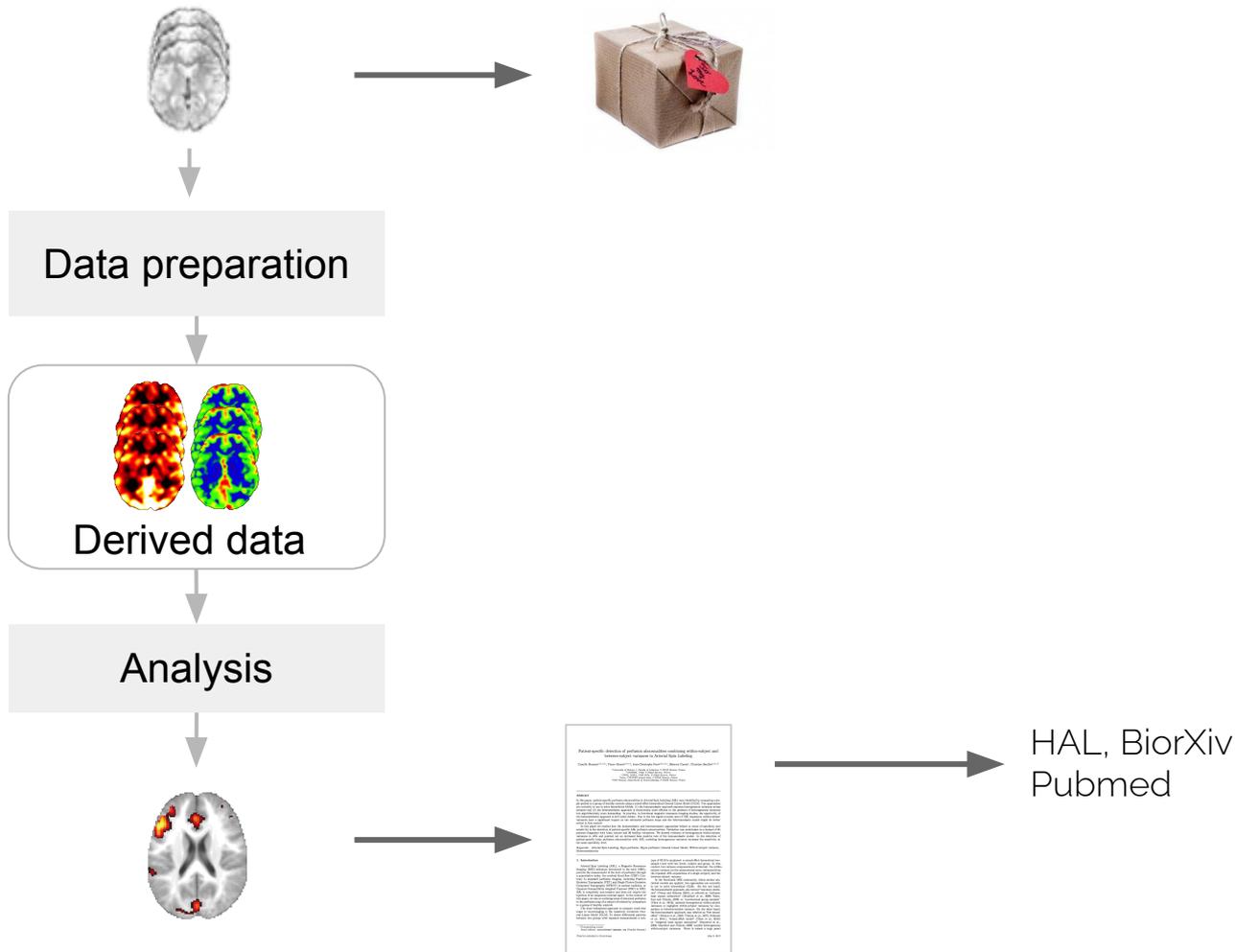
# Neuroimaging data sharing



# Neuroimaging data sharing



# Neuroimaging data sharing



# Brain Imaging Data Structure (BIDS)

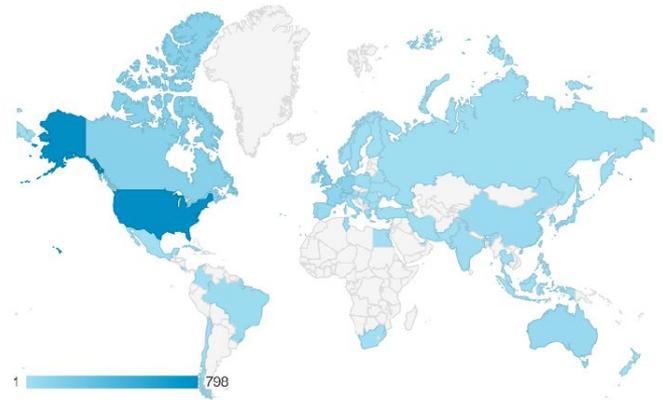
- Used in over 60 labs around the world
- Adopted by: FCP-INDI, Developing Human Connectome, SchizConnect and Donders Data repository.
- Extensions: MEG, iEEG, EEG



Krys  
Gorgolewski

(Gorgolewski et al., *Sci. Data* 2016)

Traffic to [bids.neuroimaging.io](https://bids.neuroimaging.io)



```
my_dataset/  
├── participants.tsv  
├── sub-01/  
│   ├── anat/  
│   │   └── sub-01_T1w.nii.gz  
│   └── func/  
│       ├── sub-01_task-rest_bold.nii.gz  
│       └── sub-01_task-rest_bold.json
```

# Data portability

How differences in acquisition parameters can be conveyed with enough details to support future post-processing?

- **Extend the international BIDS standard** in setting up the structures for sharing advanced MR imaging data.



## Brain Imaging Data Structure (BIDS):

A global community of 200+ members!



Guiomar  
Niso



Melanie  
Ganz



Robert  
Oostenveld

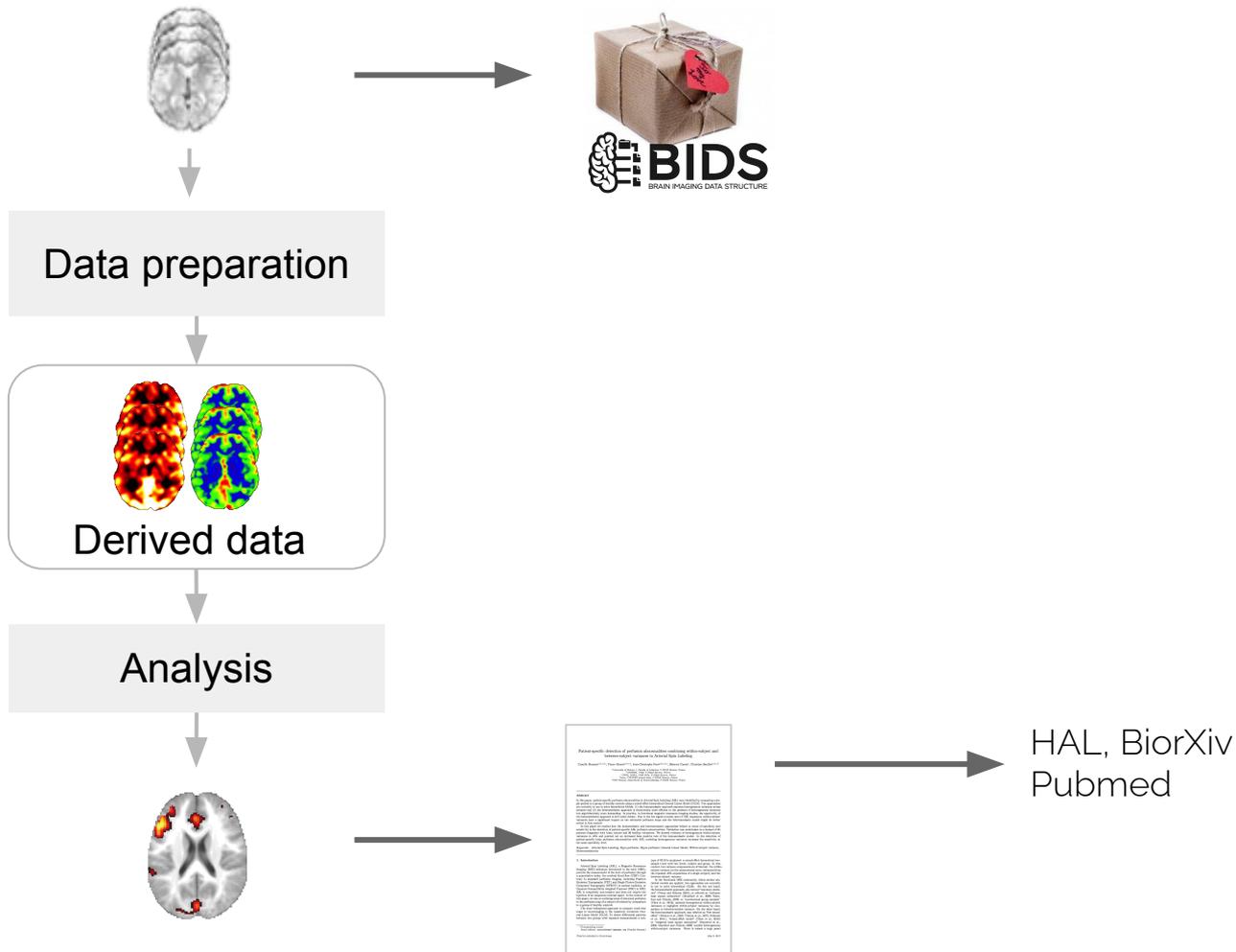


Russ  
Poldrack

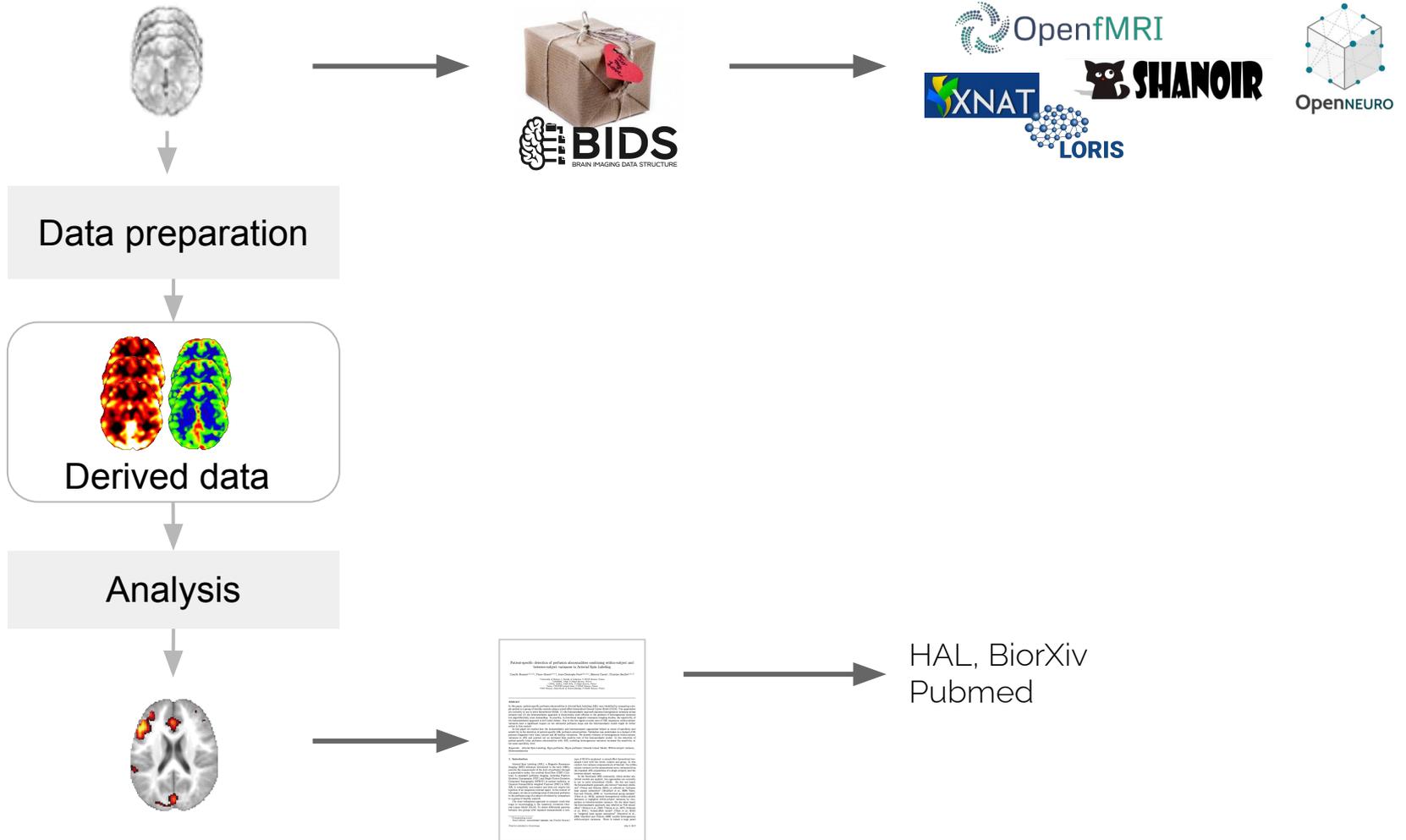


Kirstie  
Whitaker

# Neuroimaging data sharing



# Neuroimaging data sharing



# Data privacy



How to inform participants, collect consent for data sharing, and ensure de-identification of data and anonymity of metadata in accordance with GDPR?

- Review existing standards on data privacy

## Open Brain Consent (Banner et al., HBM 2020)



Stephan  
Heunis



Yarik  
Halchenko

Open Brain Consent  
stable

Search docs

- Sample consent forms
- Recommendations
- Ultimate consent form
- GDPR edition
- Anonymization tools
- Contribute
- Contact information
- Discussions

Docs » Make open data sharing a no-brainer for ethics committees. [Edit on GitHub](#)

### Make open data sharing a no-brainer for ethics committees.

[Zenodo badge](#)

#### Statement of the problem

The ideology of open and reproducible science makes its way into various fields of science. Neuroimaging is a driving force today behind many fields of brain sciences. Despite possibly terabytes of neuroimaging data collected for research daily, just a small fraction becomes publicly available. Partially it is because management of neuroimaging data requires to confirm to established legal norms, i.e. addressing the aspect of research participants privacy. Those norms are usually established by institutional review boards (IRB, or otherwise called ethics committees), which are in turn "governed" by national, federal and supra-national regulations.

Flexibility in interpretation of original regulations established in the past century, decentralization of those committees, and lack of a "community" influence over them created the problem: for neuroimaging studies there was 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 research participants' privacy. In majority of the cases, used Consent forms simply did not include any provision for public sharing of the data to get a "speedy" IRB approval for a study. Situation is particularly tricky because major granting agencies (e.g. NIH, NSF, RCUK) nowadays require public data sharing, but do not provide explicit instructions on how.

DigitalOcean Save time & money w/ the cloud platform loved by devs. Try for Free  
Sponsored - Ads served ethically

# Data privacy with GDPR



## Consent form

[Direct link](#)

To be approved and signed by participants

“[...] While the collection, use and storage of your data are done for the purpose of conducting the study to which you are currently participating, **these data might also be used for other future research projects in the field of medical and cognitive neuroscience.** [...]”

## Data user agreement

[Direct link](#)

To be approved and signed by researchers reusing the data

“[...] 2. I **will not attempt to establish or retrieve the identity of the study participants.** I will not link these data to any other database in a way that could provide identifying information. [...]”

3. I **will not redistribute these data** or share access to these data with others, unless they have independently applied and been granted access to these data, i.e., signed this Data Use Agreement. This includes individuals in my institution.  
[...]”

## Translations

- Bosnian
- Czech
- German
- Greek
- Spanish
- Finnish
- French
- Italian
- Dutch
- Norwegian
- Turkish

## French version



Anne  
Hespel



Elise  
Bannier

# Data privacy with GDPR



## Consent form

[Direct link](#)

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**11:10 Roxana Albu:**  
Re-use of data in GDPR era

## Translations

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## French version



Anne Hespel



Elise Bannier

# Data infrastructure

Which tools and databases are available and how to use them to automate multi-site integration?



- Review existing data sharing infrastructure (in Europe)

Collaboration with **ENBIT**



Daniele  
Marinazzo



Cyril  
Pernet

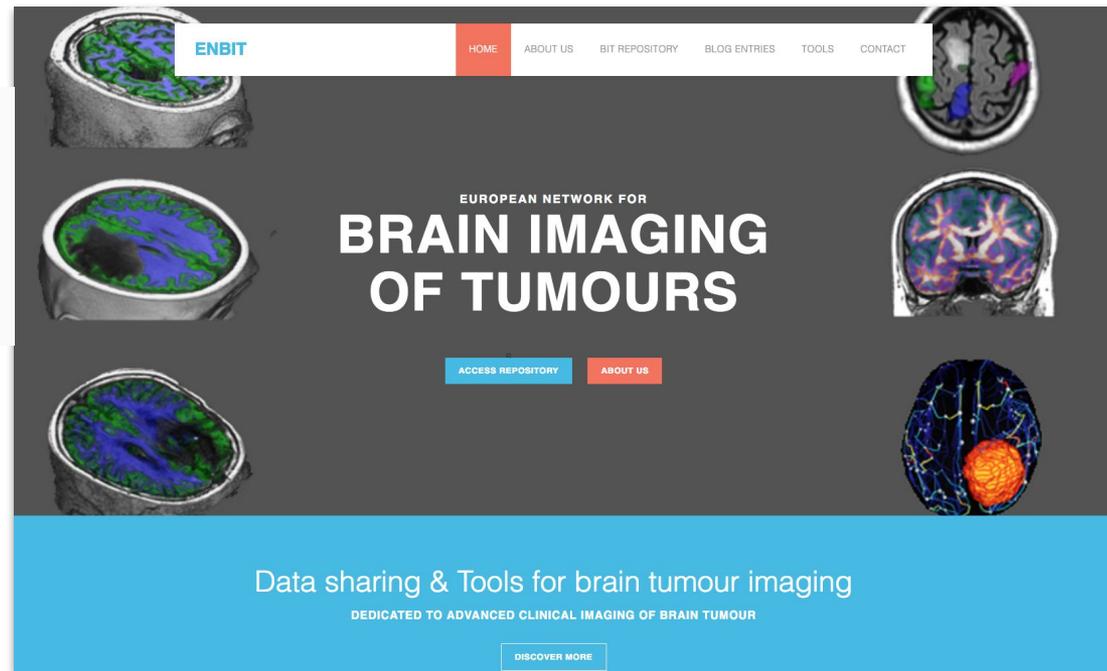


Image credits: ["Transport map"](#)

<https://en-brain-imaging-of-tumours.github.io/website/>



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# Thank you!

