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

Image credits: Sculpture by Malin Bjornsdotter "Cerebria", OHBM Brain Art SIG
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.

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.

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.

WG3 - Clinical translation
Working Group 3 focusses on fostering cross-border information exchange about past and current clinical trials and studies of glioma.

WG4 - Stakeholder relations
Working Group 4 ensures representation of all relevant stakeholders within GLiMR and acts as liaison from GLiMR to all relevant stakeholders.

WG5 - Dissemination
Working Group 5 disseminates the Action's goals and results in tailored manners to all relevant stakeholders.

https://glimr.eu/
Gliomas research in Europe

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

>> Limited samples sizes

Image credits: Sculpture by Malin Bjornsdotter “Cerebia”, OHBM Brain Art SIG
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

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...
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.

According 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.

Selection bias

The Guardian, “Why are middle-aged marathon runners faster than twenty somethings?”, Oliver Balch
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.
A brain imaging study

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

Raw data

Data preparation

Derived data

Analysis

Results
Data integration

1. Raw data
2. Data preparation
3. Derived data
4. Analysis
5. Results

Raw data
Data integration

1. Raw data
2. Data preparation
3. Derived data
4. Analysis
5. Results

Diagram showing the process from raw data to results through data preparation and derived data.
Data integration

Data preparation → Derived data → Analysis → Results

- Raw data
- Derived data
- Data preparation

11
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.

Image credits: “Privacy lock”, “Transport map”, “Mini bus”
Neuroimaging data sharing

Data preparation

Derived data

Analysis

Image credits: Parcels 1 2 & 4 (CC0), Parcel 3 (CC0), Parcel 5 (CC0).
Neuroimaging data sharing

Data preparation

Derived data

Analysis

HAL, BiorXiv

Pubmed

Image credits: Parcels 1 2 4, Parcel 3, Parcel 5.
Neuroimaging data sharing

Data preparation

Derived data

Analysis

HAL, BiorXiv
Pubmed

Image credits: Parcels 1 2 & 4 (CC0), Parcel 3 (CC0),Parcel 5 (CC0).
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

(Korgolewski et al., Sci. Data 2016)
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!

Image credits: “Mini bus”

https://bids.neuroimaging.io/
Neuroimaging data sharing

Data preparation

Derived data

Analysis

HAL, BiorXiv, Pubmed

Image credits: Parcels 1 2 & 4 (CC0), Parcel 3 (CC0), Parcel 5 (CC0).
Neuroimaging data sharing

Data preparation

Derived data

Analysis

HAL, BiorXiv, Pubmed

Image credits: Parcels 1 2 & 4 (CC0), Parcel 3 (CC0), Parcel 5 (CC0).
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
(Bannier et al., HBM 2020)

Stephan Heunis
Yarik Halchenko

Image credits: “Privacy lock”

https://open-brain-consent.readthedocs.io/
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

Image credits: “Privacy lock”
"[...] 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. [...]"

"[...] 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 been independently granted access to these data, i.e., signed this Data Use Agreement. This includes individuals in my institution. [...]"
**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](https://en-brain-imaging-of-tumours.github.io/website/)

Image credits: “Transport map”

Daniele Marinazzo  
Cyril Pernet
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Thank you!