Original Research Articles

Which infrastructure can I use to share human neuroimaging data? A survey and literature review on current solutions for EU researchers

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The ability to share research data publicly is crucial for enhancing statistical power, improving the quality of results, and ensuring the generalizability of findings. Despite the widespread availability of web-based tools and collaborative opportunities, sharing human neuroimaging data remains challenging for researchers based in the European Union (EU) due to various obstacles. In particular, many of the infrastructures available to share brain imaging data do not comply with the General Data Protection Rule (GDPR), which is applicable in the EU for all data that come from human participants. To investigate the awareness and utilization of data sharing platforms, we conducted a global survey targeting neuroimaging researchers. Our findings showed that amongst the 81 respondents, less than 50% were familiar with an infrastructure designed for EU researchers and about 20% had already shared data. Respondents also identified several key challenges, including legal compliance and privacy concerns, resource and infrastructure limitations, ethical considerations, institutional barriers, and awareness gaps. These results underscore the critical need to better publicize data sharing platforms that may be used by EU researchers. Here, we compiled a comprehensive list of infrastructures suitable for EU researchers to share brain imaging datasets from human participants.

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INTRODUCTION

In the last decade, data sharing in neuroimaging has been increasingly encouraged in order to improve reproducibility and translation of research findings into clinical use. Openly shared datasets, ranging from grassroot resources such as the 1000 Functional Connectome Project[1] or the Autism Brain Imaging Data Exchange (ABIDE[2]), to resources directly funded for the purpose of being shared with the community, such as UK Biobank[3] or the Erasmus Glioma Database,[4] have created new opportunities and changed the neuroimaging research landscape. In parallel with those large-scale initiatives, complementary efforts have aimed to facilitate sharing of smaller datasets (so called "long tail of science"[5]). These efforts have notably led to the development of standards for data organization (such as the Brain Imaging Data Structure (BIDS)[6]), but also to new data sharing platforms, such as OpenNeuro,[7] or earlier, the fMRIDC[8] in neuroimaging as well as generalist repositories.[9]

ON THE BENEFITS OF DATA SHARING

Data sharing benefits neuroimaging research by boosting statistical power, enabling new types of analyses, enhancing population representation, and improving reproducibility. First, collaboration and pooling of data across acquisition sites is a means to increase the sample sizes of research studies. Combined with other approaches such as optimizing the design of the experiment,[10] increasing sample size can be an important lever to achieve sufficient statistical power. The lack of statistical power of neuroscience studies has long been criticized,[11,12] in particular for its impact on false positive findings. In addition, pooling data is also a requirement in the case of rare diseases research, such as rare brain tumors,[13] for which the possibility to recruit participants from a single site is inherently limited. Second, with the development of analysis tools based on machine learning and deep learning techniques, larger sets of data (that may be impossible to obtain in a single center) are typically required. This is important for several applications relating to image biomarker development and validation, or radiomics. Third, data sharing enables the creation of more representative datasets that better reflect the general population. An ample literature (see for example[14] in brain imaging or[15] and[16] from preclinical research) has demonstrated how diversity in research data is a requirement to avoid biased classifiers. Finally, a growing momentum drives the sharing of individual datasets in support of research findings.[17-19] This is a key milestone for compu-

tational reproducibility (i.e., ensuring that identical results can be reproduced under the same conditions, including data, code, and methodology).

Beyond improving reproducibility and trust in scientific results, building shared datasets also creates opportunities to shape and transform the scientific culture and how science is conducted. Shared datasets provide educational opportunities and foster methodological innovation. In addition, they support global collaboration and cross-disciplinary research, enhancing the integration of interdisciplinarity into medical research. Data sharing unlocks the potential of existing datasets to generate new research ideas and hypotheses and address different research questions using the same data,[20] thus ensuring a more efficient use of the participants' time,[21] scientific funding and resources.

SUPPORT FROM FUNDING BODIES AND GOVERNMENTS

The sharing of research data is increasingly supported by funding bodies and governmental agencies, which recognize its critical role in advancing scientific research. Funding organizations such as the European Research Council (ERC) and the National Institutes of Health (NIH) often require grant recipients to adhere to open data policies.[22,23] Across Europe, many countries have implemented national frameworks and incentives to foster open science. These are very heterogeneous and range all the way from simple open access up to mandatory data sharing. Examples of European bodies with open science policy include the European Union (EU)'s and its Horizon Europe program,[24] the French National Plan for Open Science,[25] the Belgium FWO[1], the Dutch Research Council (NWO)[2], the Swiss National Science Foundation[3], Portugal's Foundation for Science and Technology[4] and the German Research Foundation[5].

BEST PRACTICES FOR DATA SHARING

Throughout the years, best practices have emerged from the scientific community, in particular, shared data should follow the FAIR and CARE guiding principles. According to FAIR, data should be Findable (i.e., data should be easy to locate), Accessible (i.e., data must be available to users), Interoperable (i.e., data should be formatted and structured in a way that allows it to work with other datasets and systems), and Reusable (i.e., data must be well-documented and licensed for use by others).[26] The CARE principles state that data should have a Collective benefit (i.e., data sharing should prioritize the benefits to communities and stakeholders involved), Authority (i.e., this principle emphasizes

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1 https://www.fwo.be/en/about-fwo/research-policy/open-access/

2 https://www.nwo.nl/en/open-science

3 https://www.snf.ch/en/VyUvGzptStOEpUoC/topic/open-access-publications

4 https://www.fct.pt/sobre/estudos-e-planeamento-estrategico/politicas-de-ciencia-aberta/

5 https://www.dfg.de/en/research-funding/funding-opportunities/programmes/infrastructure/lis/open-access

the right of individuals and communities to govern their own data), Responsibility (i.e., those sharing and using data must take accountability for their actions), and Ethics (i.e., the process must be conducted with respect, transparency, and fairness, particularly regarding sensitive or personal data).[27,28] By integrating the FAIR and CARE principles, data sharing can be more effective and responsible, ultimately leading to greater trust and collaboration in research and data use.

Additionally, incorporating patient and public perspectives is key to overcoming these challenges. Privacy loss, surveillance, and discrimination risks erode trust and reduce willingness to share data. To address this, frameworks must reflect societal values — ensuring fair benefit distribution, accountability, and open dialogue. Public involvement can be achieved through deliberative polls, citizen juries, participatory appraisals, scenario-based workshops, focus groups, and participant-led data cooperatives, as well as direct roles in data governance. For instance, dynamic consent platforms let users adjust their preferences over time.[29,30] Ultimately, these participatory approaches enhance transparency, accountability, and public trust in science.

DATA SHARING AND PRIVACY

Compliance with data protection laws, such as the General Data Protection Regulation (GDPR) in the EU (see Appendix 1 for more details) but also with equivalent regulations in non-EU countries (see Appendix 2 for an illustration), has provided important safeguards for privacy and security in neuroscience research. This legislation refers to the fundamental right of human participants to have their identity and privacy protected and has been in effect for all processing of personal data of EU citizens since 2018[6]. While these regulations aim to enhance data protection and privacy, they also introduce significant requirements in data management and sharing practices. Data protection laws vary across countries,[31-33] creating ambiguity for researchers, who may struggle to determine which platforms they are legally permitted to use.

An example of variability in definitions across geographical locations is the difference between the notion of anonymization in the United States (US) and the EU's GDPR.[34] In the US, the definition emphasizes primarily identifiable features (i.e., name, birth date, face, etc.) while the European definition states that if data can be individualized to a single participant (i.e., if data is a unique signature of a participant, such as a fingerprint), they are not anonymous and GDPR must be applied. In brief, this stricter definition of anonymization is based on the idea that individualization can lead to reidentification. A number of studies have demonstrated how reidentification can be performed based on pseudonymized data (i.e., data on which primary identifiable information has been removed, but that do not match the criteria for anonymity of the GDPR). For instance, prior research has demonstrated successful reidentification based on magnetic resonance imaging (MRI) images using publicly available face recognition software[35] but also based on face-blurred MRI images using generative adversarial networks.[36] More recently, Schwarz and colleagues[37] compared three types of commonly applied defacing software. Before defacing, 97% of MRI images were correctly matched to photographs using automated face recognition, while after de-facing with three popular software tools, automated face matching dropped to 28-38% of MRI scans. Beyond reidentification based on facial features, interindividual differences in brain connectomes can be matched among large datasets of brain images to effectively single out individuals,[38] a phenomenon known as functional MRI fingerprinting. Ravindra and Grama[39] demonstrated a de-anonymization method that utilized the uniqueness of functional MRI fingerprints to reveal the identity of individuals. We note that recent research has been more critical about the real-world risk of reidentification[40] and, in practice, there is currently no consensus on the exact definition of de-identification,[41] calling for additional research to better understand the privacy risks for participants.

GOAL OF THIS STUDY

While data sharing in neuroimaging presents significant advantages, it is fundamental to take into account privacy and ethical considerations to ensure the responsible use of sensitive information. Implementing robust security measures and adhering to data protection regulations, such as GDPR, is not only a legal requirement but also essential to maintaining the trust of participants and collaborators. In practice, to share human brain images, researchers must comply with the regulations in place in the country they are based in. In the EU, this entails complying with the GDPR and its implementations across different countries.

The strict data protection and privacy requirements for anonymization in Europe pose particular challenges for data sharing. So far, there is no up-to-date inventory available that provides an overview of platforms available to EU-based researchers. In this paper, we explore the availability, awareness, and utilization of data-sharing platforms among neuroimaging researchers. We also examine the issues and challenges researchers identify with data sharing. We focus only on sharing non-anonymous (pseudonymized) brain images (sometimes referred to as "raw data") from human participants.

Several efforts have focused on cataloging trustworthy data repositories for data sharing in research. For instance, the French Committee for Open Science (CoSO) has produced a detailed guide for selecting thematic data reposi-

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6 Note: GDPR was initially approved in 2016 and adopted in 2018

tories.[42] This guide helps researchers identify trustworthy repositories by using a set of seven criteria, including data moderation, the provision of persistent identifiers, and compliance with GDPR regulations. The CoSO's evolving list[7] currently features about 50 trusted repositories, aiming to streamline the process of sharing scientific data for French researchers. Amongst those, only nine neuroimaging platforms have passed their eligibility criteria, which include deposit moderation, issuing persistent identifiers, ensuring infrastructure longevity, minimal costs, data storage inside the EU for certain data types as well as the ability to deposit regardless of institutional affiliation. Of those nine repositories, only two have been reported by CoSO as GDPR compliant. Indeed, while GDPR-compliance is a key concern for human neuroimaging, not all neuroscience data require such stringent measures. In disciplines like preclinical electrophysiology or behavioral neuroscience for instance, data sharing can be possible without maximal GDPR constraints. This, for instance, applies to a number of repositories cited for FAIR neuroscience in a recent review by Martone.[43] Most of the platforms highlighted in this review for international neuroscience data sharing have data storage servers in the US exclusively. While US-based infrastructure has been instrumental in spearheading efforts towards the democratization of data sharing, it is not uniformly suitable for the sharing of human brain data by researchers from other countries (including in Europe) due to differences in legal frameworks and data protection regulations.

While data sharing is highly valuable for science, practitioners face several issues when trying to share data in support of research. In this study, we address a critical challenge in human neuroimaging research: selecting an appropriate infrastructure for data deposition. Specifically, we examine repositories suitable for sharing human brain imaging datasets by researchers based in the EU. Within the field of neuroscience, we put our focus on datasets from human participants as they require additional measures to comply with regulations making them effectively more difficult to share.

METHODS

SURVEY

A survey (see Appendix 3) was iteratively designed and refined with input from participants of the Glioma MR Imaging 2.0 (GliMR) collaborative network, a pan-European network of experts in glioma research (see Acknowledgements for more details). This four-section survey was shared with the scientific imaging community through various platforms, including social media (Twitter[8] [now X], Mastodon, BlueSky[9]) and the GliMR newsletter and was open for contributions in the second and third quarter of 2023.

The first section of the survey queried all respondents about their familiarity with any infrastructure suitable for EU researchers to share neuroimaging data. The second section targeted respondents who answered negatively, probing whether they encountered obstacles in sharing data or faced any impediments. On the other hand, respondents who indicated awareness of relevant infrastructure were asked to provide details, including the platform's name, URL, and whether they had previously used it to share neuroimaging data. The third section focused on participants who had already engaged in data sharing, delving into the specifics of the data types shared and whether they were linked to published papers. The final section requested participant information if they were willing to disclose such details. The Python code used to process the data from the survey is available on Gitlab[10] and archived on software heritage (swh:1:dir:a1d42e20a48847c9a7767cd7bbdd81042a71f994; origin=https://gitlab.inria.fr/empenn-public/glimr-wg2-public).

LITERATURE REVIEW

A systematic review (drawing inspiration from[44]) was carried out on Google Scholar[11] to identify infrastructures referenced in the literature as suitable for storing and sharing neuroimaging data. Journal articles published before February 2025 and whose title contained the expressions 'sharing' or 'FAIR', 'data', and 'neuroimaging' or 'neuroscience' or 'neuroinformatics' were included. The words 'platform' or 'service' or 'solution' or 'infrastructure' were also required to be part of the entry's title. Citations of articles were excluded. The exact search query run on Google Scholar is available in Appendix 4. The search results were subjected to predefined search exclusion criteria ('abstract in a journal or conference without peer review', 'retracted research article', 'research article not dedicated to a data storage infrastructure'). The third criterion comprises research articles mentioning data sharing infrastructures but whose main claim is answering a research question or providing theoretical guidelines. Application of the search exclusion criteria was performed by visually inspecting the title and the abstract of the entries when available. Of the articles about infrastructure obtained, duplicates were removed, keeping only the last entry published, as this

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7 https://www.ouvrirlascience.fr/wp-content/uploads/2024/07/ListesdesEntrepotsdeConfiance_v1bis_202407.xlsx

8 https://x.com/cmaumet/status/1676131162828296192

9 https://bsky.app/profile/jlefortbesnard.bsky.social/post/3kahervhvw52s

10 https://gitlab.inria.fr/empenn-public/glimr-wg2-public

11 https://scholar.google.fr/

is more likely to represent the latest version of the platform. One review[43] and the latest infrastructures list by the CoSO[12] (with domain being "biology" and subdomain "microscopy", "neurobiology" or "bio imagery") were added to the unique filtered research articles obtained through the search. These two resources were identified prior to the systematic search and did not appear in its results. The unique infrastructures listed in all the selected articles were extracted by carefully reading each of the articles.

EXCLUSION CRITERIA

The goal of this study was to identify infrastructures that are suitable for EU-based researchers to share raw brain datasets of living human participants. We focused on infrastructures that were suitable (and had been used at least once) to share data with the community at large (i.e., sometimes referred to as "open data"). It is important to distinguish data sharing infrastructures from software. On the one hand, an infrastructure typically includes a self-hosting or cloud-based storage solution and the administrative services required to run and maintain the infrastructure. On the other hand, a software would be the tools installed on the infrastructure specifically designed and built for the purpose of sharing data. As an example, XNAT[45][13] is an open source data-sharing software, and the XNAT Central[46][14] was an infrastructure (decommissioned in May 2024) using the XNAT software — where users could deposit and access data. Other instances of the XNAT software may be installed elsewhere (e.g., as a lab repository).

We therefore excluded: 1) software (in the absence of an associated infrastructure) as well as 2) inactive infrastructures (i.e., discontinued or in construction as of February 2025), 3) infrastructures dedicated to other types of data (including non-brain data, non-human data, derived data or data from a predefined research project), 4) infrastructures with servers located outside of the EU and 5) infrastructures whose policy terms prevented or advised not to upload personal data or metadata.

As a note, we chose to retain infrastructures in which only members of specific institutions were allowed to upload data (i.e., download open to all but upload may be restricted; see Discussion for more on this topic).

To build a comprehensive list of data sharing platforms available to EU researchers, we assessed for eligibility all unique entries shared in the survey or identified in the literature search.

RESULTS

PARTICIPANT DEMOGRAPHICS AND INFRASTRUCTURE AWARENESS

Eighty-one participants completed the survey. Of these, 40 participants (49.3%) chose to remain fully anonymous and did not provide information on their EU residency status or research involvement. Among the 41 participants (51.7%) who provided some information about their profile, all but one were based in the EU and were involved in research.

Figure 1 summarizes our main findings in terms of knowledge of an infrastructure for sharing neuroimaging data in the EU. Thirty-three participants (41%) were familiar with such infrastructure. Among them, 18 reported having previously used an infrastructure for sharing neuroimaging data covering a wide range of data types, including MRI (and derivatives, e.g., segmentations, transformation matrices), computed tomography (CT), positron emission tomography (PET), magnetoencephalography (MEG), electroencephalography (EEG), clinical and cognitive scores, and patient characteristics.

INFRASTRUCTURES SUITABLE FOR SHARING NEUROIMAGING DATA OF LIVING HUMANS

Twenty-one unique data sharing infrastructures were obtained from the survey. Nineteen research articles were obtained through a systematic literature search that described 63 unique data sharing infrastructures. By combining the infrastructures identified in the survey and those listed in the literature, we obtained 78 unique infrastructures. This initial list of infrastructures was filtered using the exclusion criteria as shown in Figure 2. 37 candidates were excluded because they did not fall within the scope of this study (10 software, 3 non-active infrastructures, 24 non-adapted infrastructures [e.g., 3 infrastructures dedicated to non-human data] and 2 only allowing the uploading of derived data). Almost three-quarters (27 out of 40) of the candidate infrastructures were then excluded because they stored their data on servers located outside of the EU. Of the 14 remaining infrastructures, 4 prohibited or advised against the uploading of personal data in their terms and conditions (see Supplementary Table 1 for the list of excluded platforms and exclusion criterion). Ultimately, 9 relevant infrastructures for the sharing of neuroimaging data from living human participants by EU researchers were obtained (see Table 1). Of those, 8 were obtained from the survey, one from the literature review and one from both the survey and the literature. This list of infrastructures is also available on Github[47] (and archived on Zenodo[48]).

Do you know of an infrastructure for EU-based researchers to share neuroimaging data?
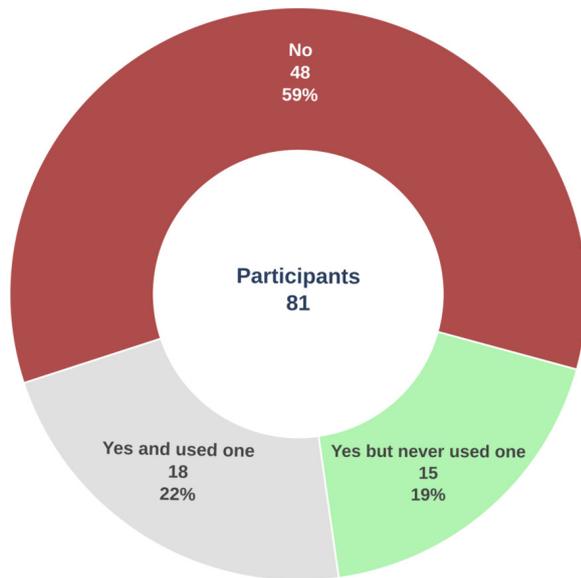
Figure 1. Awareness and usage of neuroimaging data-sharing infrastructure among survey participants.

Commitments to data preservation range widely. For example, the German Neuroinformatics Node and Ebrains Virtual Research Environment ensure data preservation for ten years, while the storage guarantee for Public nEUro is contingent upon the fees paid. However, many platforms lack clear information regarding long-term preservation strategies, which could pose risks for researchers relying on these repositories. Some platforms, such as Public nEUro[15], allow datasets to be embargoed (i.e., access is restricted to reviewers until the corresponding paper is published) for a period. Six infrastructures provide Persistent Identifiers (DOI), ensuring long-term citation and accessibility of the datasets.

CHALLENGES IN DATA SHARING FOR RESEARCHERS

In total, 25 participants (30% of the participants) shared challenges encountered when sharing data. The respondents expressed a range of issues related to sharing neuroimaging data (see Table 2). These challenges can be broadly categorized into four key areas: legal and privacy concerns, resource and infrastructure challenges, institutional barriers, and a knowledge and awareness gap.

Legal and privacy concerns were prominent, with participants noting varying interpretations of data anonymization and identification across institutions, as well as a general lack of clarity regarding the legal landscape and relevant legislation. This uncertainty complicates the data-sharing process and may deter researchers from engaging in data sharing altogether.

Resource and infrastructure challenges were also highlighted, particularly issues related to handling large datasets, the complexities of existing payment models, and the high costs sometimes associated with long-term data archiving. For example, sharing data using Dataverse NL requires institutions to pay a membership fee per year of €5,950 plus value added taxes (VAT) in 2025, and an additional cost of €330 plus VAT per terabyte (TB) per year (see https://dans.knaw.nl/en/data-services/dataversenl/). Despite efforts to address these challenges,[49] many participants expressed frustration with the lack of adequate time, incentives, and resources to develop robust data-sharing systems that are safe and sustainable over the long term.

Institutional barriers further impede data sharing. While respecting data privacy and ethics is essential to the research process, in practice they sometimes translate into lengthy administrative processes.[50] Institutional inertia, such as slow data use agreement approvals along with reluctance with those in leadership, including Principal Investigators, were also cited as significant obstacles.

Knowledge and awareness gap among researchers. Many participants were unaware of available data repository solutions and the possibilities for establishing secure data access procedures. There was also variability in how different institutions interpret the same data in terms of anonymization, pseudo-anonymization, or identifiability, which adds another layer of complexity to the data-sharing process.

DISCUSSION

The results of this survey provide insights into the current landscape of neuroimaging data sharing in the EU. It is notoriously difficult for EU-based researchers to identify an infrastructure that is suitable to share human neuroimaging data. This is well demonstrated by the fact that less than half of the respondents were aware of a data-sharing infrastructure and only about 20% had used one previously. Of note, the literature review only made it possible to identify two infrastructures. In total, we identified nine infrastructures suitable for sharing brain imaging data from human participants for stakeholders based in the EU. This list of infrastructures is also available on Github[47] (and archived on Zenodo[48]) to support further updates from the community. Many of the available repositories have the geographic locations of their servers in the US, raising potential issues for compliance with European data protection laws. While platforms like the German Neuroinformatics provide guarantees regarding sustainability, others lack clear information on long-term data preservation commitments. Some repositories, like Sikt, impose relatively high fees on data uploads, which may limit access for some researchers, while others, like the EBRAINS Virtual Research
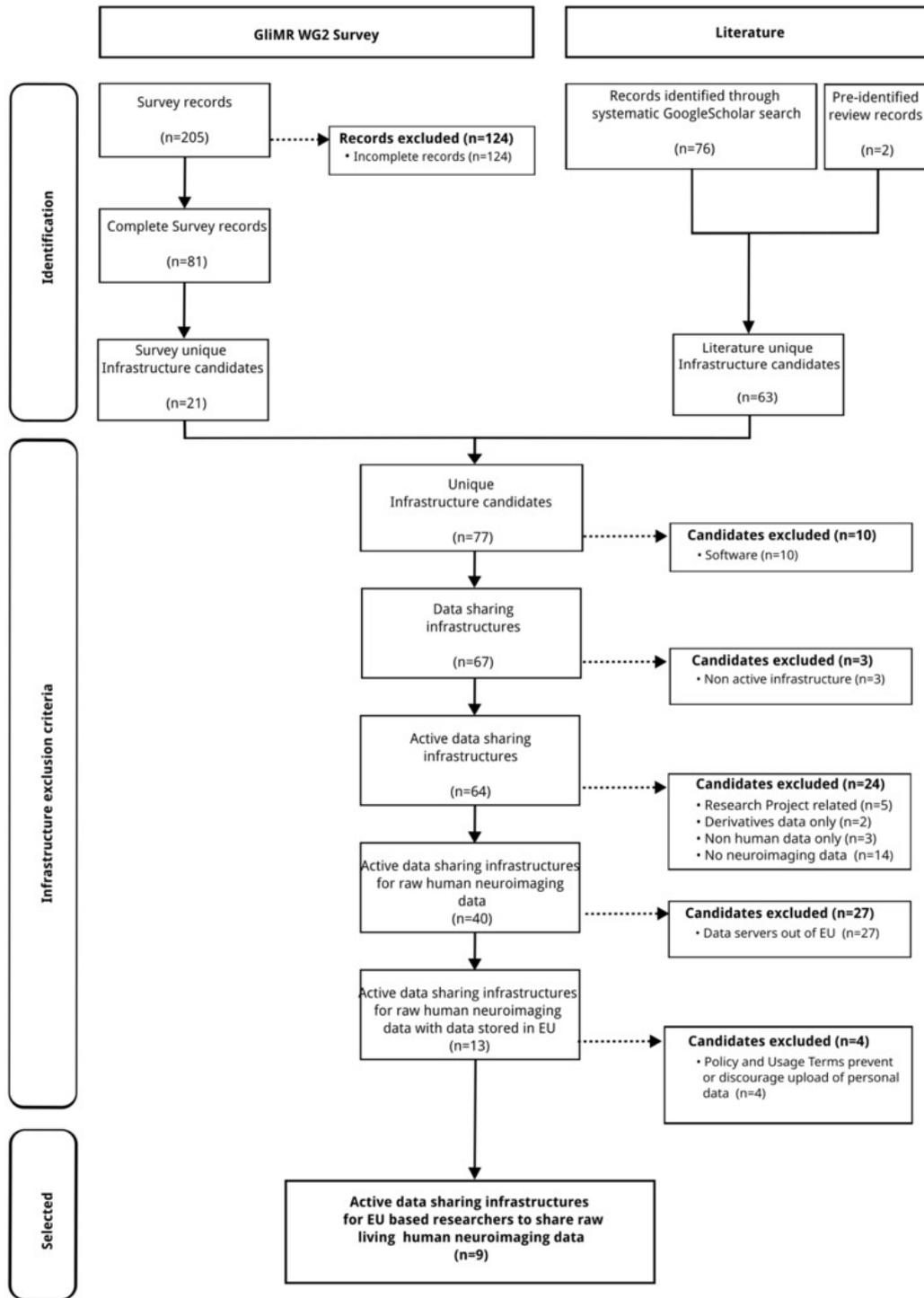

Figure 2. Selection process of the data sharing infrastructures suitable for EU-based researchers to share living human neuroimaging data. See Supplementary Table 1 for details.

Environment, offer long-term storage by relying on institutional support.

As a note (and in departure from other reviews such as[51]), we chose to retain infrastructures in which only members of specific institutions could upload data (i.e., download open to all but upload may be restricted). We believe that it is important to also highlight such platforms for two main reasons: 1) Although they cannot be used by all to upload data (as data upload is restricted to members-only), these infrastructures are open-to-all for data download. This effectively makes them relevant for the community at large and, in particular, for those interested in data reuse; 2) More importantly, this model – i.e., data sharing infrastructures in which members-only can upload but all can download – seems to be widespread in the EU. As an illustration, out of the nine platforms identified, only four offered upload open for all. We believe this is likely to ex-

Table 1. Infrastructures for sharing human neuroimaging data for researchers based in the EU stemming from a survey and literature search.

	Infrastructure	URL	Who can upload (cost)	DOI	Type of data hosted	Example of shared dataset
1	B2SHARE	b2share.eudat.eu	All scientists (free)	Yes	Cross-disciplinary research data	10.23728/B2SHARE.47AEEB85B5FF4C3CAB79A5C5B7DB49FA
2	DataverseNL	dataverse.nl	Members of DataversNL institutions (free or with fee depending on host institute)	Yes	Cross-disciplinary research data	10.34894/INHTP8
3	EBRAINS Health Data Cloud (VRE node)	vre.charite.de/vre	Employees of the Charité and collaborators, possibility to submit a request for externals (free)	Yes	Human brain data	10.25493/3VPN-ZY7
4	GIN (G-Node Data Infrastructure)	gin.g-node.org	All scientists (free)	Yes	Neuroscience data	10.12751/g-node.1lfvzi
5	Health-RI XNAT	xnat.bmia.nl	Research projects that were initiated in the Netherlands (fees apply, see pricing)	No	Medical Imaging data	xnat.health-ri.nl/data/projects/stwstrategyhn1
6	Public nEURo	publicneuro.eu	All scientists (fees apply, see pricing)	Yes	Brain Imaging Data	10.70883/QXBH2876
7	Radboud Data repository	data.ru.nl	Scientists at Radboud University (free)	Yes	Cross-disciplinary research data	10.34973/t6m1-x414
8	Shanoir Neurinfo	shanoir.irisa.fr	Collaborators of the Neurinfo platform (free)	No	Medical Imaging data	shanoir.irisa.fr then "MSSEG-2"
9	Sikt	sikt.no/en/archiving-research-data	Scientists in Norway (free)	No	Data in medical and health research, social sciences, and humanities	No brain imaging dataset currently (see sikt.no/en/find-data)

Each infrastructure is listed with its name, URL (accessed August 2025) as well as a description of who can use it for data upload (and any fees incurred by the depositor), whether it provides DOIs for shared datasets, the type of data that is hosted as well as an example of shared brain dataset, when available.

Table 2. Challenges identified by researchers when attempting to share neuroimaging data.

Category	Challenges
Legal and Privacy Concerns	Unclear legal situation and lack of knowledge about legislation. Varying interpretations of data anonymization and identification across institutions.
	Privacy concerns and ethics approval for human (clinical) data sharing.
Resource and Infrastructure Challenges	**Technical**: Difficulties with handling large datasets due to storage and transfer constraints. Absence of infrastructure and limited information about available data repository solutions.
	Fees: Difficulties with payment models of existing providers for billing processes. High costs associated with long-term data archiving.
	Credit: Inadequate time and incentive to build sharing systems with required resources, safety, and long-term maintenance.
Institutional Barriers	Inability to share data due to restrictions imposed by Principal Investigators.
	Institutional barriers including slow approval of data use agreements and de-identification processes.
	Limitations on data sharing due to regulations in specific countries.
Knowledge and Awareness Gap	Lack of knowledge about available data repository solutions.
	Limited awareness of possibilities for establishing secure data access procedures.
	Variability in considering the same data as anonymized, pseudoanonymized, or identifiable.

pand as more institutions are encouraged to provide such platforms for their own scientists.

Despite these advances, perceived and administrative barriers to data sharing remain high. The complexities of compliance, coupled with logistical and institutional hurdles, continue to impede the seamless exchange of data. Our survey revealed several challenges that researchers encounter when trying to share data, highlighting four key areas for improvement. First, it is important to clarify the legal and privacy frameworks. Establishing standardized definitions of data anonymization and identification across institutions can reduce confusion regarding compliance with relevant legislation. Second, investing in infrastructure and resources is crucial. This includes developing cost-effective solutions for handling large datasets and simplifying payment models for data storage and archiving. By providing adequate time, incentives, and resources for building sustainable data-sharing systems, institutions can foster a more collaborative environment. Third, it is essential to address institutional barriers. This may include streamlining the ethics approval process but also providing researchers with appropriate data use agreements (see the Open Brain Consent[52] for a set of templates that may be used as a basis). Institutions should also advocate for clearer guidelines on data sharing that empower researchers while ensuring regulatory compliance. Funding agencies should continue to support and develop stable databases to help take storage and sharing burdens off the shoulders of individual research institutions.[53] Finally, bridging the knowledge and awareness gap is necessary. Increasing education and training on available data repository solutions and secure data access procedures will enable researchers and data managers to utilize these tools effectively. By fostering a better understanding of data-sharing practices and addressing the variability in interpretations of data identifiability, researchers will be better equipped to engage in collaborative efforts. Additionally, addressing these challenges will only be possible by creating incen-

tives for data sharing. As an example, the development of data papers – a format allowing researchers to describe and publish their datasets as a citable publication – (see for example[54]) is a step in this direction. Beyond that, further efforts are needed to make data sharing valued as a component of scientific contributions. Finally, providing funding and support to researchers to cover the needs associated with preparing data for sharing is a requirement to encourage more widespread participation. These results are in line with the earlier survey conducted by the European Cluster for Imaging Biomarkers[17] in particular, on highlighting concerns about the time and human resources required for data sharing but also regarding the administrative and legal barriers. In contrast, fears of being pre-empted (or "scooped") was not mentioned as an issue related to data sharing in the current work. Overall, the survey findings underscore the need for clearer guidelines, improved infrastructure, and enhanced education to support more effective and widespread sharing of neuroimaging data among researchers.

It is important to recognize that our work primarily focused on the sharing of image data, which may be a limitation. In practice, image data must be accompanied by various types of metadata to be truly useful and are often complemented by other data such as questionnaires, physiological samples, psychological or diagnostic tests. In practice, the addition of further data and metadata often complexifies the assessment over the risk of reidentification.[55] In addition, we note that our estimated percentages of researchers knowing about or having used a data-sharing infrastructure is likely an overestimation. Indeed, the survey was shared using neuroimaging open science channels effectively biasing the sample towards professionals already engaged in or interested in open science. As a proxy for GDPR-compliance, we excluded infrastructures whose policy terms were explicit in preventing or advising users not to upload personal data or metadata as well as infrastructures with servers located outside of the EU. While those

two features are essential for GDPR-compliant data sharing, we note that data protection officers should always be consulted before choosing and uploading data to a platform.

While data sharing is an important lever to build more heterogeneous samples and therefore limit bias in downstream models, we note that the fairness of predictive models is a research topic in itself that goes well beyond the question of the diversity of the input datasets.[56] In addition, sampling inequalities in neuroimaging studies[57] has a strong impact on the studied population that data sharing alone will not be able to counter.

Despite the promising frameworks and support for data sharing, practical implementation is fraught with challenges. The scientific community faces conflicting expectations: while open science policies and international scientific cooperation demand extensive data sharing and pooling of smaller studies for meta- and mega-analyses to achieve broader perspectives and more precise conclusions, the GDPR emphasizes personal data minimization and privacy protection. This discrepancy sometimes creates confusion amongst researchers which can lead to reluctance in sharing data. Inter and intra-country variations in data management practices further complicate the situation. Focusing on these issues in future research could pave the way for establishing a European consensus on best practices for neuroimaging data sharing. This could help mitigate inconsistencies and promote uniform standards across institutions, ultimately facilitating more effective and compliant data sharing practices.

CONCLUSION

This work has outlined the unique challenges and complexities associated with sharing brain imaging data in a GDPR-compliant environment. In total, we identified nine data sharing infrastructures, suitable for researchers based in the EU to share brain imaging datasets. The survey highlighted the lack of awareness among researchers about the available platforms for sharing imaging data, underlining the urgent need for clearer guidelines and enhanced educational efforts. In addition, we have identified legal and privacy concerns, resource and infrastructure challenges, institutional barriers, and knowledge and awareness gaps as four key obstacles to effective data sharing.

The future of neuroimaging data sharing hinges on publicizing existing GDPR-compliant infrastructures as well as fostering new robust and GDPR-compliant solutions that facilitate both data protection and accessibility. Future efforts should focus on building cross-border consensus on best practices, enhancing awareness, and developing incentives for data sharing. Funding bodies and research institutions must play a crucial role in supporting initiatives that

provide stable, long-term repositories aligned with FAIR and CARE principles.

DATA AND CODE AVAILABILITY

The Python code used to process the data from the survey is available on Gitlab[16] and archived on software heritage (swh:1:dir:a1d42e20a48847c9a7767cd7bbdd81042a71f994; origin=https://gitlab.inria.fr/empenn-public/glimr-wg2-public).

The raw and processed survey data are not publicly available due to the presence of personally identifiable information, for which explicit consent for public sharing was not obtained.

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16 https://gitlab.inria.fr/empenn-public/glimr-wg2-public

CONFLICTS OF INTEREST

Alexandre Pron was a contributor to the Shanoir software (see Shanoir contributor list) as part of his work funded by FLI-IAM (see Fundings section). **Camille Maumet** was part of the leadership of the Shanoir software as president of the Executive Committee of the Shanoir Consortium. The Shanoir Neurinfo infrastructure managed by the Neurinfo platform is regularly used in research projects of the Empenn team of which **Jeremy Lefort-Besnard**, **Alexandre Pron** and **Camille Maumet** were a part. **Vera Keil** joined the EUCAIM consortium in March 2025 with her institution. EUCAIM glioma data is shared via XNAT/Health-RI, but **Vera Keil** does not have an official function in XNAT. **Stephan Heunis** developed the open source software tool datalad-catalog that the Public nEURo system uses as the frontend for findability and accessibility of the datasets that they host. However, he is not involved in the Public nEURo project in any other way shape or form, they just use the software that he created at his current employment with funding support from several sources (see Funding Sources section).

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17   https://www.cost.eu/actions/CA18206/

REFERENCES

1. Biswal BB, Mennes M, Zuo XN, et al. Toward discovery science of human brain function. *Proc Natl Acad Sci USA*. 2010;107(10):4734-4739. doi:10.1073/pnas.0911855107

2. Di Martino A, Yan CG, Li Q, et al. The Autism Brain Imaging Data Exchange: Towards Large-Scale Evaluation of the Intrinsic Brain Architecture in Autism. *Mol Psychiatry*. 2014;19(6):659-667. doi:10.1038/mp.2013.78

3. Miller KL, Alfaro-Almagro F, Bangerter NK, et al. Multimodal population brain imaging in the UK Biobank prospective epidemiological study. *Nature Neuroscience*. 2016;19(11):1523-1536. doi:10.1038/nn.4393

4. van der Voort SR, Incekara F, Wijnenga MMJ, et al. The Erasmus Glioma Database (EGD): Structural MRI scans, WHO 2016 subtypes, and segmentations of 774 patients with glioma. *Data in Brief*. 2021;37:107191. doi:10.1016/j.dib.2021.107191

5. Ferguson AR, Nielson JL, Cragin MH, Bandrowski AE, Martone ME. Big data from small data: data-sharing in the "long tail" of neuroscience. *Nat Neurosci*. 2014;17(11):1442-1447. doi:10.1038/nn.3838

6. Gorgolewski KJ, Auer T, Calhoun VD, et al. The brain imaging data structure, a format for organizing and describing outputs of neuroimaging experiments. *Scientific Data*. 2016;3(1):160044. doi:10.1038/sdata.2016.44

7. OpenNeuro. A free and open platform for sharing MRI, MEG, EEG, iEEG, ECoG, and ASL data - OpenNeuro. 2021. Accessed March 28, 2021. https://openneuro.org/

8. Van Horn JD, Gazzaniga MS. Why share data? Lessons learned from the fMRIDC. *NeuroImage*. 2013;82:677-682. doi:10.1016/j.neuroimage.2012.11.010

9. Stall S, Martone ME, Chandramouliswaran I, et al. Generalist Repository Comparison Chart. Published online July 15, 2020. doi:10.5281/zenodo.3946720

10. Kang K, Seidlitz J, Bethlehem RAI, et al. Study design features increase replicability in brain-wide association studies. *Nature*. 2024;636(8043):719-727. doi:10.1038/s41586-024-08260-9

11. Button KS, Ioannidis JPA, Mokrysz C, et al. Power failure: why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience*. 2013;14(5):365-376. doi:10.1038/nrn3475

12. Marek S, Tervo-Clemmens B, Calabro FJ, et al. Reproducible brain-wide association studies require thousands of individuals. *Nature*. Published online March 16, 2022. doi:10.1038/s41586-022-04492-9

13. Clement P, Booth T, Borovečki F, et al. GliMR: cross-border collaborations to promote advanced MRI biomarkers for glioma. *Journal of medical and biological engineering*. 2021;41:115-125. doi:10.1007/s40846-020-00582-z. PMID:33293909

14. Li J, Bzdok D, Chen J, et al. Cross-ethnicity/race generalization failure of behavioral prediction from resting-state functional connectivity. *Science Advances*. 2022;8(11):eabj1812. doi:10.1126/sciadv.abj1812

15. Larrazabal AJ, Nieto N, Peterson V, Milone DH, Ferrante E. Gender imbalance in medical imaging datasets produces biased classifiers for computer-aided diagnosis. *Proceedings of the National Academy of Sciences*. 2020;117(23):12592-12594. doi:10.1073/pnas.1919012117

16. Voelkl B, Vogt L, Sena ES, Würbel H. Reproducibility of preclinical animal research improves with heterogeneity of study samples. *PLOS Biology*. 2018;16(2):e2003693. doi:10.1371/journal.pbio.2003693

17. Giehl K, Mutsaerts HJ, Aarts K, et al. Sharing brain imaging data in the Open Science era: how and why? *The Lancet Digital Health*. 2024;6(7):e526-e535. doi:10.1016/S2589-7500(24)00069-4

18. Nichols TE, Das S, Eickhoff SB, et al. Best practices in data analysis and sharing in neuroimaging using MRI. *Nat Neurosci*. 2017;20(3):299-303. doi:10.1038/nn.4500

19. Poldrack RA, Baker CI, Durnez J, et al. Scanning the horizon: towards transparent and reproducible neuroimaging research. *Nature Reviews Neuroscience*. 2017;18(2):115-126. doi:10.1038/nrn.2016.167

20. TEHDAS Consortium Partners. *Report on Secondary Use of Health Data through European Case Studies*.; 2022.

21. Brakewood B, Poldrack RA. The ethics of secondary data analysis: considering the application of Belmont principles to the sharing of neuroimaging data. *Neuroimage*. 2013;82:671-676. doi:10.1016/j.neuroimage.2013.02.040

22. Liu J, Carlson J, Pasek J, Puchala B, Rao A, Jagadish HV. Promoting and enabling reproducible data science through a reproducibility challenge. Published online 2022. doi:10.1162/99608f92.9624ea51

23. Shopova S. Open Access Guidelines for research results funded by the ERC. Published online 2016.

24. European Commission DG for R and I. *Horizon Europe, Open Science: Early Knowledge and Data Sharing, and Open Collaboration*. Publications Office of the European Union; 2021.

25. Badolato AM. National plan for Open Science | 4th July 2018. Ouvrir la Science. November 17, 2018. Accessed January 16, 2025. https://www.ouvrirlascience.fr/national-plan-for-open-science-4th-july-2018

26. Wilkinson MD, Dumontier M, Aalbersberg IJJ, et al. The FAIR Guiding Principles for scientific data management and stewardship. *Scientific data*. 2016;3(1):1-9. doi:10.1038/sdata.2016.18. PMID:26978244

27. CARE Principles. Global Indigenous Data Alliance. Accessed August 4, 2025. https://www.gida-global.org/care

28. Carroll SR, Garba I, Figueroa-Rodríguez OL, et al. The CARE Principles for Indigenous Data Governance. *Data Science Journal*. 2020;19(1). doi:10.5334/dsj-2020-043

29. Kalkman S, van Delden J, Banerjee A, Tyl B, Mostert M, van Thiel G. Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *J Med Ethics*. 2022;48(1):3-13. doi:10.1136/medethics-2019-105651

30. Nwebonyi N, Silva S, de Freitas C. Public Views About Involvement in Decision-Making on Health Data Sharing, Access, Use and Reuse: The Importance of Trust in Science and Other Institutions. *Front Public Health*. 2022;10. doi:10.3389/fpubh.2022.852971

31. Eke DO, Bernard A, Bjaalie JG, et al. International data governance for neuroscience. *Neuron*. Published online 2021. doi:10.31234/osf.io/esz9b

32. Molnár-Gábor F, Sellner J, Pagil S, Slokenberga S, Tzortzatou-Nanopoulou O, Nyström K. Harmonization after the GDPR? Divergences in the rules for genetic and health data sharing in four member states and ways to overcome them by EU measures: Insights from Germany, Greece, Latvia and Sweden. *Seminars in Cancer Biology*. 2022;84:271-283. doi:10.1016/j.semcancer.2021.12.001

33. Vlahou A, Hallinan D, Apweiler R, et al. Data Sharing Under the General Data Protection Regulation. *Hypertension*. 2021;77(4):1029-1035. doi:10.1161/HYPERTENSIONAHA.120.16340

34. Eke D, Aasebø IEJ, Akintoye S, et al. Pseudonymisation of neuroimages and data protection: Increasing access to data while retaining scientific utility. *Neuroimage: Reports*. 2021;1(4):100053. doi:10.1016/j.ynirp.2021.100053

35. Schwarz CG, Kremers WK, Therneau TM, et al. Identification of anonymous MRI research participants with face-recognition software. *New England Journal of Medicine*. 2019;381(17):1684-1686. doi:10.1056/NEJMc1908881. PMID:31644852

36. Abramian D, Eklund A. Refacing: reconstructing anonymized facial features using GANs. In: IEEE; 2019:1104-1108. doi:10.1101/447102

37. Schwarz CG, Kremers WK, Wiste HJ, et al. Changing the face of neuroimaging research: Comparing a new MRI de-facing technique with popular alternatives. *NeuroImage*. 2021;231:117845. doi:10.1016/j.neuroimage.2021.117845. PMID:33582276

38. Finn ES, Shen X, Scheinost D, et al. Functional connectome fingerprinting: identifying individuals using patterns of brain connectivity. *Nature neuroscience*. 2015;18(11):1664-1671. doi:10.1038/nn.4135. PMID:26457551

39. Ravindra V, Grama A. De-anonymization attacks on neuroimaging datasets. In: ; 2021:2394-2398. doi:10.1145/3448016.3457234

40. Jwa AS, Koyejo O, Poldrack RA. Demystifying the likelihood of reidentification in neuroimaging data: A technical and regulatory analysis. *Imaging Neuroscience*. 2024;2:1-18. doi:10.1162/imag_a_00111

41. Chevrier R, Foufi V, Gaudet-Blavignac C, Robert A, Lovis C. Use and understanding of anonymization and de-identification in the biomedical literature: scoping review. *Journal of medical Internet research*. 2019;21(5):e13484. doi:10.2196/13484. PMID:31152528

42. de Lamotte F, Stoll V, Arènes C, et al. *Selecting a Trustworthy Subject-Specific Repository for Self-Depositing Data: Methodology and Analysis of Existing Services*. Comité pour la Science Ouverte; 2024. doi:10.52949/81

43. Martone ME. The past, present and future of neuroscience data sharing: a perspective on the state of practices and infrastructure for FAIR. *Front Neuroinform*. 2024;17. doi:10.3389/fninf.2023.1276407

44. Guillot P, Bøgsted M, Vesteghem C. FAIR sharing of health data: a systematic review of applicable solutions. *Health Technol*. 2023;13(6):869-882. doi:10.1007/s12553-023-00789-5

45. Marcus DS, Olsen TR, Ramaratnam M, Buckner RL. The extensible neuroimaging archive toolkit. *Neuroinform*. 2007;5(1):11-33. doi:10.1385/NI:5:1:11

46. Herrick R, Horton W, Olsen T, McKay M, Archie KA, Marcus DS. XNAT Central: Open sourcing imaging research data. *NeuroImage*. 2016;124:1093-1096. doi:10.1016/j.neuroimage.2015.06.076

47. Inria-Empenn/glimr_eu_infra: A list of infrastructures for sharing human neuroimaging data for researchers based in the EU. Accessed August 4, 2025. https://github.com/Inria-Empenn/glimr_eu_infra

48. Lefort-Besnard J, Pron A, Clement P, et al. Inria-Empenn/glimr_eu_infra. doi:10.5281/zenodo.16735588

49. Jwa AS, Poldrack RA. The spectrum of data sharing policies in neuroimaging data repositories. *Human Brain Mapping*. 2022;43(8):2707-2721. doi:10.1002/hbm.25803. PMID:35142409

50. Jwa AS, Norgaard M, Poldrack RA. Can I have your data? Recommendations and practical tips for sharing neuroimaging data upon a direct personal request. *Imaging Neuroscience*. 2025;3:imag_a_00508. doi:10.1162/imag_a_00508

51. Lamotte F de, Stoll V, Arènes C, et al. *Sélectionner un entrepôt thématique de confiance pour le dépôt de données: méthodologie et analyse de l'offre existante*. Comité pour la Science Ouverte; 2024. doi:10.52949/52

52. Open Brain Consent. The Open Brain Consent: Informing research participants and obtaining consent to share brain imaging data. *Human Brain Mapping*. Published online 2021. doi:10.1002/hbm.25351

53. Data sharing is the future. *Nature Methods*. 2023;20(4):471-471. doi:10.1038/s41592-023-01865-4

54. Gorgolewski K, Margulies D, Milham M. Making Data Sharing Count: A Publication-Based Solution. *Frontiers in Neuroscience*. 2013;7. doi:10.3389/fnins.2013.00009

55. Simon GE, Shortreed SM, Coley RY, et al. Assessing and Minimizing Re-identification Risk in Research Data Derived from Health Care Records. *EGEMS (Wash DC)*. 2019;7(1):6. doi:10.5334/egems.270

56. Birhane A. The Limits of Fairness. In: *Proceedings of the 2022 AAAI/ACM Conference on AI, Ethics, and Society. AIES '22*. Association for Computing Machinery; 2022:2. doi:10.1145/3514094.3539568

57. Chen Z, Hu B, Liu X, et al. Sampling inequalities affect generalization of neuroimaging-based diagnostic classifiers in psychiatry. *BMC Med*. 2023;21(1):241. doi:10.1186/s12916-023-02941-4

58. European Commission. Widening participation and spreading excellence - European Commission. 2025. Accessed February 11, 2025. https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/widening-participation-and-spreading-excellence_en

APPENDICES

APPENDIX 1: GUIDING PRINCIPLES OF THE GENERAL DATA PROTECTION REGULATION (GDPR)

Navigating GDPR challenges when sharing neuroimaging data in the EU requires careful consideration of data protection principles and compliance with the GDPR (see https://www.consilium.europa.eu/en/policies/data-protection-regulation/). Key considerations include establishing a lawful basis for data processing, such as obtaining explicit consent or demonstrating the necessity for scientific research. It is imperative to collect and share only the minimum required data, clearly articulating the purpose of sharing and ensuring alignment with the original data collection purpose. Additionally, obtaining informed consent from participants, implementing robust security measures, and considering anonymization techniques to mitigate re-identification risks are crucial steps. Secure data transfer mechanisms, meticulous documentation, and prompt response to data subject rights further contribute to GDPR compliance. Obtaining approval from ethics committees, conducting Data Protection Impact Assessments (DPIA) and establishing collaboration agreements, and are essential components of responsible data sharing practices.

A multidisciplinary approach involving legal experts, data protection officers, and researchers is vital for navigating these challenges effectively amidst the evolving landscape of data protection regulations.

APPENDIX 2: DATA PROTECTION REGULATIONS BEYOND THE EUROPEAN UNION

Under Horizon Europe, the European Commission provides funding for research and innovation projects to enhance research and innovation capabilities across Europe. The Widening Participation and Strengthening the European Research Area (WIDERA) sub-program plays a crucial role in advancing research and innovation capacity for a broader set of countries that may be lagging behind, aligning with the overarching policy objectives of the European Research Area (ERA). This initiative seeks to address disparities in research and innovation capabilities among EU members and associated countries, promoting a more balanced and integrated research landscape across the continent. The current list of associated countries that could apply for WIDERA calls include Albania, Armenia, Bosnia & Herzegovina, Faroe Islands, Georgia, Kosovo, Moldova, Montenegro, North Macedonia, Serbia, Tunisia, Türkiye, and Ukraine.[58]

However, data sharing between EU countries and non-GDPR-compliant regions poses challenges, particularly as WIDERA encourages international cooperation, requiring adherence to both GDPR and national regulations on personal data protection.

In Turkiye, for example, the Personal Data Protection Law No. 6698 (KVKK) aligns closely with GDPR, imposing strict regulations on personal data transfers. Both GDPR and KVKK classify health data as sensitive and require robust protection measures. Researchers must ensure compliance with GDPR's cross-border data transfer rules, including obtaining explicit consent or implementing adequate protection measures. Recent amendments to the KVKK, effective June 1, 2024, have restructured the framework for cross-border data transfers by allowing transfers under certain conditions without explicit consent, provided that appropriate safeguards are in place. These changes facilitate international research collaborations by reducing administrative hurdles while ensuring data protection.

APPENDIX 3: SURVEY

Which infrastructure to share neuroimaging data in Europe?

This questionnaire is about identifying databases for neuroimaging data sharing that can be used by scientists based in Europe.

Question 1
Do you know of an infrastructure (database, website, etc.) that can be used by researchers based in Europe to share neuroimaging data?
Yes / No

If yes to question 1:

Question 2
What is the name of the infrastructure (e.g. Donders Repository)
Question 3
What is the URL of the sharing infrastructure? (e.g. https://data.donders.ru.nl/?0)
Question 4
Any other information you would like to share with us?
Question 5
Is the platform compliant to the European General Data Protection Regulation (GDPR)?
Yes/No
Question 6
Have you ever used this infrastructure to share data?
Yes/No

If yes to question 6:

Question 7
If your data was associated with a paper, could you share the article url?
Question 8
What type of data did you share? (MRI, CT, PET, SPECT, EEG, MEG, etc...)

Question 9
Did you face any issues while sharing data? Or are there any issues that prevented you from sharing data?
Question 10
Would you like to stay anonymous
Yes/No

If yes to question 10

Question 11
Are you based in Europe?

> **Yes/No**
> Question 12
> Are you working in research?
> **Yes/No**

APPENDIX 4: LITERATURE REVIEW

The systematic literature search was carried out using the following Google Scholar query launched on 31 March 2025: "allintitle: (('FAIR' OR 'sharing' OR 'data') AND (('neuroscience' OR 'neuroimaging' OR neuroinformatics' OR "brain") AND ('platform' OR "solution" OR "repository" OR "service" OR "infrastructure"))) -site:arxiv.org -site:biorxiv.org -site:ssrn.com -site:researchgate.net"

In the query, the main preprint sharing sites such as biorxiv.org have been excluded in order to focus on articles that went through to the peer review process. Article citations were excluded from the query results.

Please note that Google Scholar does not allow filtering to the nearest month in queries and URLs. Also, for the reproducibility of the search, it will be advisable to exclude results obtained after 6 February 2025 (date of the last result obtained).

SUPPLEMENTARY MATERIALS

Supplementary Table 1

Download: https://apertureneuro.org/article/144839-which-infrastructure-can-i-use-to-share-human-neuroimaging-data-a-survey-and-literature-review-on-current-solutions-for-eu-researchers/attachment/303664.csv