Paris Brain Institute

ICM

Paris Brain Institute Data Policy

To ensure research integrity, respect open science values, and maximize value of research discoveries

Table of content

Introduction

This document presents the policy concerning all research data at Paris Brain Institute. The purpose of the policy is to ensure that research is conducted with integrity, and that the output is made available as openly as possible, to maximize their value to scientific progress.

This document has been written by the Paris Brain Institute's Data Governance Committee. It is composed of members of the Scientific Steering Committee and representatives of all parties involved in data management.

This document is also a guideline for the management and sharing of research data, software, and code. It summarises recommended best practices that Paris Brain Institute requires or recommends researchers to implement throughout the research process. It provides a framework within which the research teams and platforms can, as much as possible, elaborate their own data protocol.

Paris Brain Institute supports researchers in the application of this policy by providing the operational resources they need to implement the best possible practices.

The data policy applies to all staff working for Paris Brain Institute, regardless of their employer or the site where they carry out their activity. It applies to scientific staff, including researchers, engineers, project leaders, doctoral students, post-doctoral students, as well as to all technical, regulatory, or administrative support staff involved in the design and implementation of scientific projects. In addition, the partners and staff of external organisations are concerned by this policy, by participating in its respect and application in their respective areas.

The implementation of this policy is the overall responsibility of the General Management of the Paris Brain Institute, which supports this policy.

Each director, platform or biobank/databank manager, and team leader is responsible, within his or her own area, for implementing the policy and ensuring its application with the support of the various support functions, as well as ad hoc bodies and networks of referents.

The implementation of this policy is based on seeking the support of all and requires everyone to take responsibility. Staff will be able to benefit from the gradual deployment of essential equipment, tools and organisation aimed at facilitating everyone's appropriation of a data management culture and rules of good practice aimed at making this policy operational.

Paris Brain Institute considers that datasets and research software are legitimate products of research eligible for evaluation and recognises that the activity of data management and software development are an integral part of the research process contributing to the quality of research. Furthermore, Paris Brain Institute recognises software as exploitable products of research, which may give rise to remuneration depending on the Institute agreement in force. Data management plans, as well as other initiatives put in place to manage and distribute data and software code, will be considered in the institute's evaluations.

Purpose of this policy

Research data are a driving force behind academic research. Research data management refers to the careful organisation and management of research data throughout the research cycle. The careful handling of research data is essential for the reliability, quality, and reproducibility of research, as well as promoting the reuse(ability) of research data.

At Paris Brain Institute, the research ecosystem (research teams and platforms) uses, manipulates, and generates large quantities of digital and non-digital data and relies on the development of software of varying complexity, from short scripts to complex applications. The collection or production of data should respect the legal framework designed to protect persons regarding the processing of their personal data, to protect the quality and the integrity of the data and comply with intellectual property rights of all third parties. The international research community is also expected to ensure the preservation, sharing and reuse of the products of scientific research. This global movement, involving researchers, policy makers and funders, aims at improving the quality, integrity, and reproducibility of research.

Paris Brain Institute works closely - and has partnership agreements - with public institutions involved in research, higher education, and care (e.g., CNRS, INSERM, APHP, Sorbonne University), and other IHU, joint research units (UMRs) and public–private partnerships. Furthermore, many collaborations occur with international institutions, e.g., through funding from the European Commission or the National Institutes of Health, USA. Defining the common principles on which to build trust in the quality of data and defining the rules for securing access and appropriate use, requires an agreement on guidelines, an individual commitment to comply with such guidelines, and an organization based on specialized expertise to help researchers fulfil such commitment. The current policy is an important milestone in strengthening the policy on scientific integrity that the institute is engaged with.

Legal context

All phases of research must comply with current regulations and legislation, including the General Data Protection Regulation (GDPR[1]), the French law of 6 January 1978 relating to information technology, files, and freedoms[2], and the European and national regulation relating to clinical research[3]. During all phases of research, the work must be carried out in line with applicable codes of conduct, including the Codes of Conduct for Research Integrity[4], and the code of ethics and professional conduct of Paris Brain Institute. Additional codes of conduct that are relevant for some discipline(s), such as Genomics or Artificial Intelligence, and those that will develop in the future, must be respected as well. Paris Brain Institute guidelines for managing and sharing research data and software code are aligned with the requirements of research funding bodies and journal publishers and respect the **FAIR**[5] principles promoted by the European Open Science Cloud[6] association.

Area of application

This policy applies to any public or private scientific personnel (researchers, engineers, project managers, doctoral students, post-docs etc.) working at Paris Brain Institute, as well as to any technical, regulatory, or administrative support personnel involved in the design and implementation of scientific projects.

The policy covers all digital and non-digital research data, e.g., factual records (numerical files, textual records, images, movies, and sounds) used as primary sources for scientific research, and that are commonly accepted in the scientific community as necessary to validate research findings.

It applies to all research projects conducted at Paris Brain Institute subject to existing contract or agreements. It also applies to all software components (scripts, programs, or workflows) and to more elaborate software developed at the Paris Brain Institute.

Summary

Paris Brain Institute aims at ensuring the widest possible access to its world-class research in accordance with the principal: “as open as possible, as closed as necessary”. The data policy aims at raising awareness of best practices among researchers and providing the operational resources to implement them. The objective of this data policy is to specify the roles, rights and responsibilities of each stakeholder concerning Paris Brain Institute policy for the management of research data and software. The strategy of Paris Brain Institute is to provide the necessary support and resources to implement the policy, and to solicit feedback from managers, PIs, and researchers to revise the policy on a regular basis.

1 https://gdpr-info.eu/
2 https://fra.europa.eu/en/law-reference/act-ndeg78-17-6-january-1978-data-processing-data-files-and-individual-liberties
3 https://www.ema.europa.eu/en/human-regulatory/research-development/clinical-trials/clinical-trials-regulation
4 https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/guideline-for-promoting-research-integrity-in-research-performing-organisations_horizon_en.pdf
5 https://www.go-fair.org/fair-principles/
6 https://eosc-portal.eu/

Distribution of responsibilities

The board of directors establishes the policy frameworks for data management and evaluates it on a regular basis. Processes for (external) evaluation will be put into place. It provides adequate central facilities and support at central level to facilitate responsible data management. It monitors compliance with the Data Management Regulations on a regular basis.

The Executive Director of Paris Brain institute is responsible for endorsing the institute's data policy. The Executive Director is responsible for ensuring that the institute data protocol is evaluated on a regular basis. The Executive Director is accountable to the Board committee for the elaboration and implementation of the data policy within the institute and any deviations from the Data Management Regulations.

The Data committee is responsible for establishing and updating the data policy to be reviewed by the board of directors.

Managers responsible for controlling or administering researchers, employees or students are responsible for informing them of the data policy, ensuring that they comply with the relevant rules, and, where necessary, holding them accountable.

The Principal Investigators (research leader, project leader, or the equivalent thereof) holds day-to-day responsibility for the effective management of data generated or obtained from their research: from data collection, data processing to data publication. It is responsible for compliance with the Data Management Regulations, the institute data policy, and the legal, ethical, and contractual requirements concerning research data throughout the research project. The Principal Investigator is accountable to his or her supervisor in this matter. The Principal Investigator is responsible for drawing up (or having someone else draw up), regularly updating, and archiving the Data Management Plan (DMP). The Principal Investigator is responsible for making the necessary agreements with employees and students involved in the research project concerning the management of research data.

The researchers and engineers are responsible for working according to the Data Management Regulations and the faculty/institute data protocol and implementing data management within the research project in accordance with the Data Management Plan (DMP) and the applicable guidelines and codes of conduct. This includes making every reasonable effort to keep an accurate and comprehensive record of their research, including documenting clear procedures for the collection, storage, use, reuse, access and retention or deletion of the research data associated with their research.

Role, rights, and responsibilities of the institution

Paris Brain Institute is committed to providing:

- The necessary support, advice, and information to researchers on all aspects of research data management.
- A robust and secure infrastructure to facilitate proper management and secure storage of research data and software.
- The necessary tools for storage infrastructure, capacity and access management, data retention and backup policy.
- Tools for robust and compliant management of research data.
- A support to researchers in the application of this policy by providing checklists and documentation to help adopt good practices, and to navigate the available resources.
- Training courses and in-person support to help researcher adopt good practices, and to use the available resources.

Role, rights, and responsibilities of the researcher

Creating, archiving, and updating the Data Management Plan

A **Data Management Plan** (DMP) must be put in place as soon as a possible, and not later than at the time of the project application. A first version of the DMP must be created in the OPIDOR[7] platform using the institute's template and updated regularly until the project ends. The template is adapted to Paris Brain Institute's data policy, includes explanations and examples tailored to the institute's research activities, and is compliant with the ERC and ANR requirements. OPIDOR is a machine-actionable platform developed by Inist-CNRS, a service unit of the CNRS, and includes a working group at the Paris Brain Institute that maintains the templates based on feedback from researchers and platforms.

Paris Brain Institute offers support for DMP creation by sending a request to dmp@icm-institute.org. The Data Analysis Core will then be in contact to schedule a support session. Training sessions are also regularly provided[8].

Preparing data collection

Before conducting research involving third parties, clear agreements must be made on how research data will be collected, processed, accessed, used, and stored, as well as on copyrights and rights of use. These are articulated in a partnership, MDTA (Material and Data Transfer Agreement) or DTA (Data Transfer Agreement), consortium or similar agreements and are reviewed or written by the Legal department of the Institute. A checklist is available to help formulate the agreement[9]. It is highly recommended to finalize the DMP beforehand, so that this can be included in the agreement without the need to redefine it in the agreement.

Paris Brain Institute encourages researchers to reuse existing (open source) code and software before developing new ones (catalog of IT solutions available on the intranet). When using existing software and code, the potential consequences imposed by user licences should be investigated. The DSI (IT Department) assists in making existing repositories available within the IT infrastructure and hosts a GitLab server for collaborative development and code sharing.

Researchers must check whether legal constraints apply to their research project before any data are created or collected. A checklist is provided to check for legal constraints[10]. Researchers can consult the Technical and Regulatory Committee (CART) to help clarify and conform to legal and regulatory requirements. The CART reviews projects submitted to them monthly, and includes the Legal office, DPO, the RIPH cell (when human subjects are involved), DSI, RIS, ROQ and DAC.

Storage requirements, computational needs, access permissions to the data must be defined together with the DSI (IT Department) before any data are created or collected and updated throughout the research project. Each researcher has its own storage space on the DSI servers for research data and can request the creation of a new space for each research project, with access limited to the people involved in the project. It is recommended that these storage spaces are organized based on a **classification scheme**. To make it easier to find and identify data according to **FAIR principles**, a precise and consistent shared naming convention must be adopted[11].

Preparing personal data collection

Prior to project implementation, CNIL[12] authorization is required unless the project complies with a reference methodology. If the project complies with a reference methodology, the compliance of the project must be documented internally. Reference methodologies can be found here[13]. A checklist and templates for submission to CNIL are made available[14]. The first-level assessment of compliance will be carried out by the researcher, using these tools. In addition to its support within the CART committee, the DPO will assist in the construction of authorisation requests for strategic, complex, or innovative research that must be submitted to the CNIL.

The Institute asks researchers to anticipate all solutions for the future use of personal data. Best practice is to inform participants in the informed consent for that data and biological samples might be used for other health research purposes and to refer participants to a specific information device, such as a website, for or updates on data use. Our **Data Transparency Portal** is available for this purpose[15].

A data protection impact assessment (PIA) must be created when a type of processing is likely to result in a high risk to the rights and freedoms of natural persons, adapted to the sensitivity of the data and the level of risk. E.g., high-risk sensitive data includes data that reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership. It is prohibited to process genetic and biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited. A checklist will be provided to identify the sensitivity and level of risk13. The analysis is carried out by the data manager (and by delegation, the scientific manager of the project) and validated by the DPO and ROQ.

In the case of an exchange of **personal data** with third parties, an agreement concerning the handling of this data must be drawn up in line with current legislations and supervised by the Legal department of the Institute. Transfers of personal data outside the European Union when data is transferred from European territory to a country that do not apply European data protection provisions thoroughly anticipated and must be regulated. A checklist and templates on data sharing agreements are available[16].

7 https://opidor.fr/planifier/
8 https://dac.institutducerveau-icm.org/service/training/
9 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#checklist-and-templates-data-sharing
10 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#checklist-and-templates-data-collection
11 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#file-naming
12 https://www.cnil.fr/fr
13 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#cnil-reference-methodologies
14 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#cnil-checklist-and-templates
15 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#data-transparancy-portal
16 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#checklist-and-templates-data-sharing

Collecting data

To make it easier to use and reuse data, the investigators should use open, standard, and interoperable formats and the creation of **metadata** as soon as the first data are generated.

Metadata that belong to non-digital data should be digitized as much as possible and done so according to **FAIR** principles.

The Institute encourages researchers to contact the IT front office prior to data collection to inform themselves about the recommended software and resources for data collection, storage, and analysis.

Collecting personal data

For projects involving humans, data must be **pseudonymized** prior to their use for research purpose using the in-house tool Identity Manager[17], which provides the appropriate level of security of an Electronic Case Report Forms (eCRF) designed to comply with legal constraints. Training for using Identity Manager is regularly provided[18].

Reusing data

When applicable, Paris Brain Institute encourages researchers to reuse data. **Datasets** that are reused must be cited in publications. Paris Brain Institute considers **datasets** to be legitimate, citable products of research in accordance with the Joint Declaration of Data Citation Principles[19].

Data reuse must comply with legal provisions and contractual requirements. Researchers can consult the Technical and Regulatory Committee (CART) to help clarify and conform to legal requirements, and to ensure that the study sponsor agrees to reuse of the data or samples. The CART reviews projects submitted to them monthly, and includes the Legal office, DPO, the RIPH cell (when human subjects are involved), DSI, RIS, ROQ and DAC.

Data sets that are reused must be cited in publications.

Reusing personal data

Data must be reused in a manner that is transparent to the data subjects. The reuse of personal data is considered processing of data. This means that research participants must be informed of this. Anticipating this requirement by using a **Data Transparency Portal** at the onset of the study is highly recommended, as this will decrease the required administrative burden for future studies. Only the re-use of anonymous (not pseudo-anonymous) personal data is not subject to the information obligation.

Processing data

Research data must be handled securely to guarantee the integrity, availability, and – where required – confidentiality of the data. All necessary measures should be taken to prevent loss, damage, or unauthorized use or manipulation, in compliance with appropriate policies on information security and privacy. Access and actions on data must be tracked and documented, and appropriate data quality and consistency checks must be in place, in accordance with those that have been defined at the onset of the study.

Research data must be regularly backed-up in managed, controlled storage areas. Paris Brain Institute strongly recommends using the infrastructure provided by the DSI (IT Department) to process and store research data and scientific software, considering the sensitivity of the data.

Metadata describing the processes applied to the data should be created and linked to the data as soon as they are created and for as long as they are processed. **Metadata** should describe the category of data (research data, personal data, sensitive data, etc.) so that appropriate data processing and storage solutions can be applied. The use of an Electronic Case Report Forms (eCRF) is highly recommended, as well as the use of digital tools designed to manage the data management process when they exist, such as REDCap, XNAT and OMERO. DSI (IT Department) provides a list of available software solutions, and are available for additional requests.

Publishing data

Before publishing **datasets**, data must be stored and distributed using tools appropriate to the sensitivity level of each type of data and must only be accessible to authorized people.

Paris Brain Institute encourages the distribution, publication and sharing of research data and software code according to the principle “as open as possible, as closed as necessary“. In other words, data and code sharing is expected to be shared within the limits posed by legal or contractual obligations, including the protection of identity (GDPR) and contractual obligations with the sponsor or the data controller. A checklist will be provided to help determine if, and how, data can be shared[20].

Paris Brain Institute requests the researchers to publish the data underlying the study together with their publication. They are particularly encouraged to publish negative results (including data that will not give rise to a peer-reviewed article). A list of online data repositories will be provided[21].

Paris Brain Institute encourages the publication of **data papers**, which are peer-reviewed publications that present and describe a **dataset** which can be cited in the same way as any other publication.

If access to the data after publication must remain restricted, Paris Brain Institute asks that the **metadata** be accessible so that the existence of the data and the conditions for access are known.

When datasets are published, they should be correctly described, documented, and contextualized. To comply with the requirements of funding bodies, the publication of data must follow **FAIR principles**, and must always be associated with a **distribution and usage license**.

17 https://idmanager.icm-institute.org/login

18 https://dac.institutducerveau-icm.org/service/training/

19 https://force11.org/info/joint-declaration-of-data-citation-principles-final/

20 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#checklist-and-templates-data-sharing

21 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#data-sharing-and-archiving-repositories

Archiving data

At the end of each research project, and before the research project is closed, researchers are expected to preserve the data produced in a specific preservation space to ensure their sustainability. To ensure data are comprehensible and reusable, the data deposited in this space must be correctly documented and recorded in a sustainable format when possible. A list of sustainable formats and conversion tools can be found here[22].

Researchers must check the regulations and legal or contractual constraints on preservation applying to their data. In the case of personal data, the law requires data to only be collected and preserved if they are «adequate, relevant and limited» to what is necessary for the purposes for which they were collected or processed. In general, only data that is mandatory or beneficial in the long term should be stored, including:

- Data subject to legal or contractual obligations relating to preservation.
- Data with evidential value (for example: study pre-registration).
- Data that can be used for the reproducibility of scientific work.
- Unique data that are non-reproducible or difficult to reproduce.

Archiving personal data

Personal data must be retained, destroyed, or anonymised during or after completion of a research project in accordance with GDPR. If personal data will be made available to other research teams later, it is important to determine:

- The duration of data retention for the processing of personal data necessary for the study for which authorization is requested.
- The duration of the data retention for the purpose of processing necessary for the constitution of the collection of biological samples/data repository aimed at re-using the data for research purposes.

The minimal legal retention period of research data (excluding **personal data**) is defined by specific legislation, codes of conduct, contractual terms, or demonstrable agreements within the discipline point to a different retention period. It is therefore important to ensure that the retention period for **personal data** is consistent with, and justified by, the purpose for which they are processed. A distinction should be made between:

- Current use (retention of data in the «active base») when they are necessary, in the immediate working environment, for the teams in charge of implementing the study (duration of inclusions and follow-up and post-publication controls).
- The archiving of data in accordance with the regulations in force, when the data are no longer used but are still of administrative, historical, scientific, or statistical interest to the organization.

Development of software, hardware designs, and analysis scripts

Paris Brain Institute aims at ensuring the widest possible access to its world-class research in accordance with the principal: “as open as possible, as closed as necessary.” If software, hardware designs, code, or analysis scripts can be distributed, Paris Brain Institute recommends making the source code public, providing packages, and registering the software in a software catalogue.

Paris Brain Institute encourages all researchers developing software components, whether they are scripts, programs, hardware designs, or workflows, to follow best development practices. These include tools for versioning, documentation, testing and the use of Source code hosting facilities (e.g., Gitlab). The DSI (IT Department) is available for advice on coding standards and guidelines. The procedures for integrating, developing, and hosting new applications can be found on intranet.

Researchers are also encouraged to include versions of software, code, hardware designs, libraries, and operating systems to allow the rebuilding of the software execution environment.

Before software is distributed, researchers should verify whether it can be used for commercial/industrial purposes in accordance with the rules imposed by funding bodies. If so, the Innovation Directorate must be contacted without delay for the purpose of an invention disclosure. Likewise, when researchers are contacted by a commercial company about software they have published, they must contact the Innovation Directorate.

Software must always be released with a **distribution and usage licence**. The choice of licence may have repercussions for the future exploitation of the software (e.g., commercial, academic, free).

To enable others to find and cite the correct version of the software code (e.g., the version used and cited in a publication), Paris Brain Institute recommends submitting the published version to Software Heritage[23] to ensure it is permanently available and citable.

When researchers reuse third-party software or software components, they must cite each software component reused in their publications. Paris Brain Institute considers software to be legitimate, citable products of research in accordance with the Software Citation Principles[24].

22 https://gitlab.com/icm-institute/dac/data-management/-/wikis/home#sustainable-formats-conversion-tools-and-code

23 https://www.softwareheritage.org/

24 https://force11.org/info/software-citation-principles-published-2016/

APPENDIX

Glossary

Classification schemes
The classification scheme is the tree structure of directories and files, with names anyone can understand, common to a project or an entity, such as a project acronym. The classification scheme helps anyone to find data more easily and to pass on information in a context of regular staff turnover (doctoral students, post-docs, fixed-term contracts etc.).

Data paper (or data article)
A peer-reviewed scientific publication that aims primarily to describe one or more datasets. The data described must be accessible, either in the form of appended data files or via a permanent link to the data repository where they are stored. The data paper can be published in a data journal (a journal that only publishes data papers) or a conventional scientific journal.

Data repository
A repository for storing research data and enabling them to be found and reused thanks to a metadata description. There are many data repositories of diverse types: disciplinary, multidisciplinary, specific to a publisher, institutional etc.

Data underlying publications
Data needed to validate the results presented in scientific publications.

Data Management Plan
The Data Management Plan is an evolving summary document that helps to organise and foresee all the stages in the data life cycle. It is drafted at the beginning of a research project and regularly updated. It explains how the research data collected or generated are managed during and after the project.

Dataset
A dataset is a grouping of similar or connected data gathered to form a coherent whole. A dataset must always be accompanied by metadata so that it can be easily understood and reused.

Distribution and usage licence
A distribution licence is a legal instrument that supplements copyright. It enables the rightsholder of a work to grant to users in advance certain rights to use the work.

FAIR principles
The FAIR principles (Findable, Accessible, Interoperable, Reusable), published in 2016, constitute guidelines and best practices for improving the reuse of research data. With slight adaptation, the principles can also be applied to research software.

Metadata
Metadata are structured information that describes data or a resource. Metadata accompany data to enable the scientific community to access, understand and reuse them.

Metadata standards
Metadata standards are models that specify all the metadata needed to describe a resource. For example, the Minimum Information about a Genotyping Experiment (MIGen) describes all the metadata required to be able to understand and reuse data arising from a genotyping experiment.

Naming rules
Adopting precise, shared naming rules is essential to locate and identify data, avoid problems during transfer and enable data to be preserved in the medium and long term. A few rules to be respected: give a brief, explicit name, including the project acronym, do not use spaces or special characters, indicate the version, etc.

Pseudonymization
Pseudonymization is a data management and de-identification procedure by which personally identifiable information fields within a data record are replaced by one or more artificial identifiers, or pseudonyms. A single pseudonym for each replaced field or collection of replaced fields makes the data record less identifiable while remaining suitable for data analysis and data processing.
Pseudonymization is one way to comply with the European Union's General Data Protection Regulation (GDPR) demands for secure data storage of personal information. Pseudonymized data can be restored to its original state with the addition of information which allows individuals to be re-identified. In contrast, anonymization is intended to prevent re-identification of individuals within the dataset.

Personal data
Personal data refers to any information relating to an identified or identifiable natural person. The notion of personal data covers a broad scope that includes both directly identifying data and indirectly identifying data. The identification of natural persons can be carried out directly from a single piece of data (first and last name). The identification of natural persons can also be carried out indirectly in particular by reference to an identifier (e.g. patient number) or from crossing of a set of data such as factors specific to the physical, physiological, genetic, mental, economic, cultural, or social identity.
In practice, to reduce the sensitivity of the data, researchers use pseudonymization by replacing directly identifying data (first and last name) in a dataset with indirectly identifying data (e.g., patient number).

Software Management Plan
A Software Management Plan (SMP) is an evolving document describing a piece of research software, how it is designed and developed, its goals, who it is for, the results expected and obtained, its potential distribution, intellectual property information etc. throughout the life cycle of the software.

Research
The creative work undertaken on a systematic basis to increase the stock of knowledge, including knowledge of humankind, culture and society, and the use of this stock of knowledge to devise new applications.

Research data
The recorded information (regardless of the form of the media in which it may exist) necessary to support or validate research project's observations, findings, or outputs.

Sustainable format
A format can be considered "sustainable" if it is open (its internal specifications are freely accessible), widely used and standardised (if possible). Open, standard, and interoperable formats. An open format is a format whose functional and technical specifications are public and available free of charge (or at a low cost). An open and standardised format (e.g., the ISO 19005 - standardised PDF/A format) is interoperable, meaning that data recorded in this type of format are independent of the software used to create them as they can be read and modified by any software designed to process this type of file (image, text, audio etc.).

Unique, persistent identifier (or PID for Persistent Identifier)
A unique, persistent identifier enables a digital resource to be identified uniquely and cited. It guarantees a stable link to the online resource by establishing a permanent correspondence between the resource's identity and its location on the web.

25 https://gdpr.eu/article-4-definitions/

Supporting documents and references

- Rapport de l'office parlementaire des choix scientifiques et technologiques sur « Pour une science ouverte, réaliste, équilibrée et respectueuse de la liberté académique » – mars 2022

- Rapport de l'office parlementaire des choix scientifiques et technologiques sur « Promouvoir et protéger une culture partagée de l'intégrité scientifique » – mars 2021

- Feuille de route du CNRS pour la science ouverte – novembre 2019

- Plan national pour la science ouverte – juillet 2018

- European Commission website: https://ec.europa.eu/info/research-and-innovation/strategy/strategy-2020-2024/our-digital-future/open-science/european-open-science-cloud-eosc_en

- Promouvoir et protéger une culture partagée de l'intégrité scientifique Pratiquer une recherche intègre et responsable-guide. Comité d'éthique du CNRS – mars 2017

- The European Code of Conduct for Research Integrity. All European Academies. 2017

- Charte de déontologie et d'intégrité scientifique de l'Agence nationale de la recherche – 2018

- The legal framework for the use of personal data in the context of the institute's research activities, is provided by the following main texts:
    - Le règlement européen n°2016-679 du 27 avril 2016, dit RGPD pour « règlement général sur la protection des données » ; https : //www.cnil.fr/fr/reglement-europeen-protection-données
    - La loi n°78-17 du 6 janvier 1978, dite « loi Informatique et Libertés », modifiée par la loi n°2018-493 du 20 juin 2018 et son décret d'application n°2019-536 du 29 mai 2019 ;
    - La loi n°2012-300 du 5 mars 2012 relative aux recherches impliquant la personne humaine, dite loi Jardé, modifiée par l'ordonnance n° 2016-800 du 16 juin 2016 ;
    - Les lois n° 2016-41 du 26 janvier 2016 de modernisation de notre système de santé et n° 2019-774 du 24 juillet 2019 relative à l'organisation et à la transformation du système de santé, pour ce qui concerne le Système national des données de santé
    - The «Data Protection Officer» section of the ICM intranet includes a presentation of these different texts and recommendations specific to Paris Brain Institute

- Engagement de la Direction et Déclaration de la politique de protection des données personnelles, 28 janvier 2022

- Management Commitment and Privacy Policy Statement Paris – 28 January 2022

- Ethics and professional conduct charter of Paris Brain Institute

- Charte d'éthique et de déontologie de l'Institut du Cerveau

- Guide des services de la Direction des Applications de la recherche de l'Institut du Cerveau

- Guide de la DSI

Credits

Scientific Steering Committee: Jean Christophe Corvol, Brian Lau, Liane Schmidt and Jacobo Sitt

Ethical committee member and data management expert: Ségolène Aymé
Data Analysis Core (DAC): Mathias Antunes, Stephen Whitmarsh, Violetta Zujovic
DSI (IT Department): Stéphane Chaillou
Data protection officer (DPO): Frédérique Lesaulnier
Legal office: Mathilde Gibert
Research integrity officer (RIS): Claire Levy-Marchal

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