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¹ Use one of the following codes:

R: Document, report (excluding the periodic and final reports)

DEM: Demonstrator, pilot, prototype, plan designs

DEC: Websites, patents filing, press & media actions, videos, etc.

OTHER: Software, technical diagram, etc.

² Use one of the following codes:

PU = Public, fully open, e.g. web;

CO = Confidential, restricted under conditions set out in Model Grant Agreement;

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Abstract

The European Platform for Neurodegenerative Diseases (EPND) has created a ‘Technical Hub’ digital infrastructure to centralize and harmonize access to biosample collections and datasets for neurodegenerative disease research. The EPND Hub integrates metadata and data access workflows from multiple federated repositories, providing a centralized catalogue that facilitates dataset discovery, access requests, and interoperability with existing infrastructures.

This report, provided as deliverable D1.6, documents EPND services for requesting access to data (Data Access Request, DAR) and samples (Sample Access Request, SAR) via the EPND Hub. A number of access request scenarios are presented, depending on the technical solutions and existing processes specific to different resource providers. For each access request workflow, a short demonstration video shows how different personas (i.e., researcher, data provider) interact with the EPND Hub via web-based user interface (UI) components to request access or to handle the request, respectively.

This deliverable D1.6 validates the workability of requesting and receiving access decisions and respective sample and/or data using the different workflows currently supported by the EPND Hub.

Introduction

The European Platform for Neurodegenerative Diseases (EPND) has created a ‘Technical Hub’ digital infrastructure to centralize and harmonize access to biosample collections and datasets for neurodegenerative disease (ND) research. The EPND Hub integrates metadata and data access workflows from multiple federated repositories, providing a centralized catalogue that facilitates dataset discovery, access requests, interoperability with existing infrastructures, and an analytics environment provided by the Alzheimer’s Disease (AD) Data Initiative’s AD Workbench (ADWB).

Currently, the EPND Catalogue lists over 100 neurodegeneration cohorts, accompanied by their data sets and sample collections. The EPND Hub references data from the AD Data Initiative’s AD Workbench (ADWB), Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), the Luxembourgish node of ELIXIR (ELIXIR-LU), and the European Medical Information Framework for Alzheimer’s Disease (EMIF-AD) catalogue, with planned expansions to Biobanking and BioMolecular resources Research Infrastructure-European Research Infrastructure Consortium (BBMRI-ERIC) and the European infrastructure for translational medicine (EATRIS). EPND’s interfaces allow contributors to add and edit metadata records directly in the Hub, or to syndicate them through an API-driven mechanism, where the catalogue can automatically pull and update dataset information from sources, reducing the need for manual entry. Additionally, federated discovery of assets from other catalogues is under development to enable finding and displaying in the EPND Hub additional resources in response to specific user queries. Admin functions allow the EPND team to manage the Hub, e.g., review and approve the catalogue entries, supervise syndication, oversee the metadata flows, or manage the contact and access applications submitted by users to the Hub itself.

On top of enhanced discovery, the EPND Hub facilitates accessing the data and samples by providing EPND users with a streamlined, federated access request process across the above-mentioned data providers, allowing researchers to use a single portal and login credentials to discover, request, and access a wide range of diverse datasets. At the same time, the data providers can still manage access in accordance with local governance and legal standards while maintaining overall process consistency and transparency. The EPND Hub has implemented two types of resource access request procedures, namely the data access request (DAR) (Fig. 1) and the sample access request (SAR) (Fig. 2). The request process is initialized and tracked by a central Brokerage Service of EPND (<https://discover.epnd.org>), where its status can be followed by the researcher. Depending on the owner of the requested resource, the request is forwarded to the target infrastructure of the data or sample provider who handles the request and ultimately grants access to the resources according to their internal policies and data use conditions. The EPND Hub will also enable the data owners to handle the incoming access requests directly in the EPND Hub in its administrative panel.

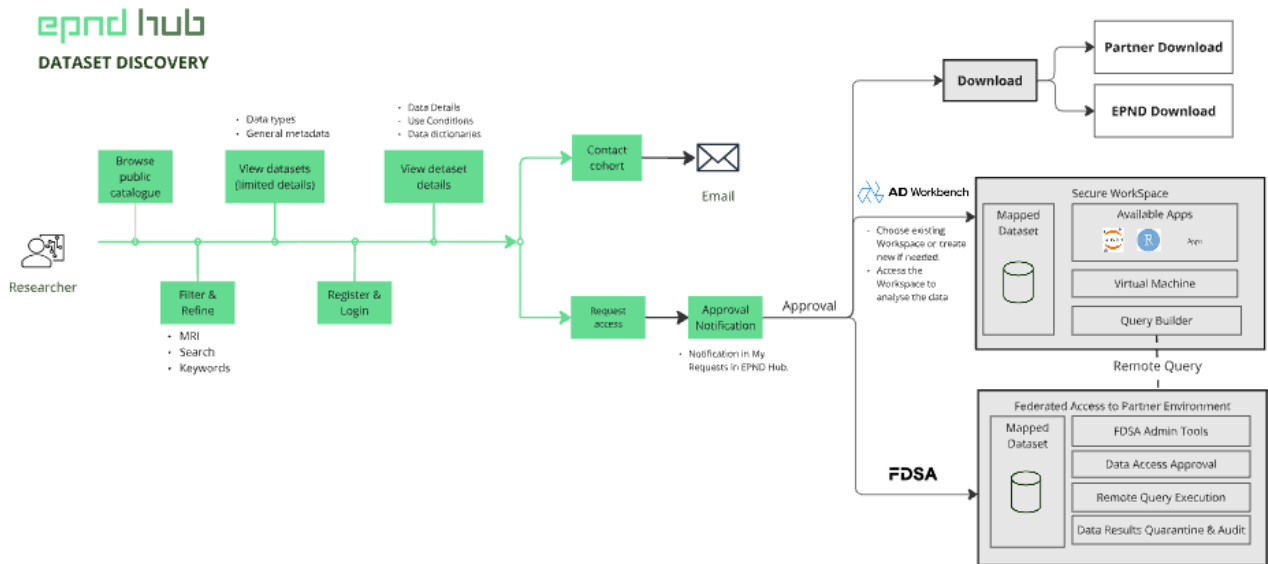


Figure 1. Data discovery and access workflow — a user journey

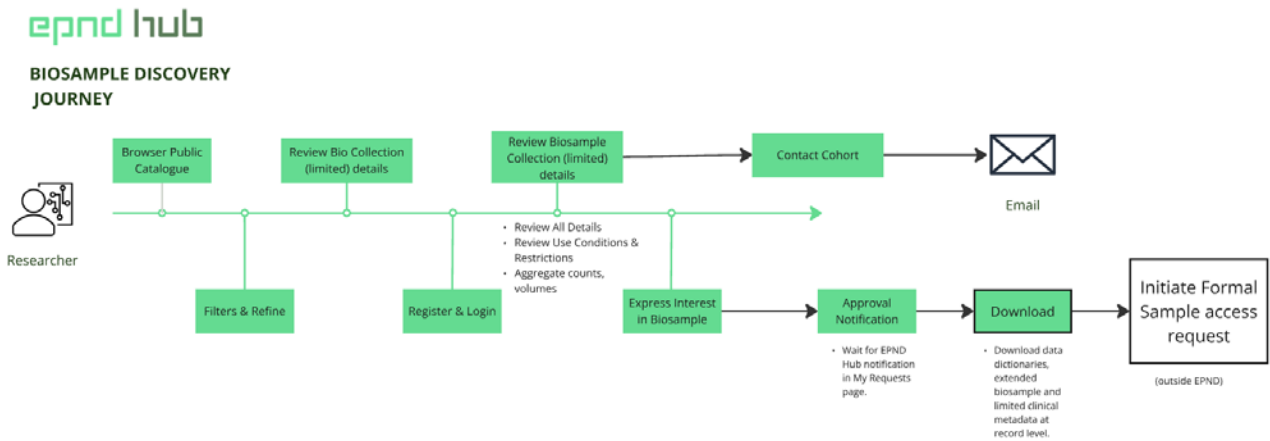


Figure 2. Sample discovery and access workflow — a user journey

In this report, we document different access request scenarios, exemplifying the technical solutions for submitting and handling requests that can be specific to different providers. For each scenario, a short video shows how different personas (i.e., researcher, data provider) interact with the EPND Hub via web-based UI components.

Methods

The ambition of the EPND Hub is to centralize and harmonize discovery and access to biosample collections and datasets for neurodegenerative disease research. Multiple Work Package (WP) 1 project meetings and discussions were devoted to designing the solution that would streamline the existing access procedures of EPND partners and external data providers through the EPND Hub.

The specific goals of the common data & sample request brokerage solution were to:

- Offer a single access point for EPND platform users, where all user's requests can be initiated and tracked (to facilitate the requesting process and ensure coherent data user experience)
- Provide a convenient request handling interface for data providers, where all the received requests can be reviewed, and access decisions can be registered, tracked, and shared with the users (to facilitate the approval process and ensure convenient data provider experience)
- Integrate with the existing access procedures of data providers, so that the handling of requests received from EPND can be done consistently irrespective of the request origin (to avoid adding complexity to the approval process and ensure coherent data provider experience, in accordance with local governance and legal standards while maintaining overall process consistency and transparency)
- Enable automation of data access upon a positive decision, so that the data can become available for the users as soon as the approval is granted (to reduce data provider's efforts in provisioning the data, and accelerate the process)

The requirements and characteristics of DAR and SAR processes that exist at EPND data providers were collected and analysed. Based on this landscape analysis, the EPND Brokerage Service was designed and implemented to flexibly yet coherently support multiple scenarios for data and sample access requests. It involves multiple workflows that are dependent on the data storage location and their data management systems, as well as individual requirements of certain resources or resource providers.

The EPND Brokerage Service has been integrated in the EPND platform catalogue (<https://discover.epnd.org>) and currently (i.e., as of August 2025) supports EPND users in requesting access to 110+ datasets and 35+ sample sets. Further extensions for customizations of the data-provider specific workflows and integration with existing infrastructures are continually being developed.

As part of this Deliverable, current workflows are showcased on selected resources from the EPND catalogue. Where possible, the demonstrations involve two perspectives to show interaction with the UI components of the platform and email communication involved:

- a researcher/applicant perspective — a step-by-step guide of getting access to the data or samples,
- a data provider/cohort owner perspective — a demo of request handling in different technical setups.

The Deliverable D1.6 demonstration has been designed as follows:

1. The demonstration of the different use cases has been done during different project meetings, including public webinars and the demonstration of the milestone M1.7 (Implemented Minimum Viable Product (MVP) of the EPND Platform node of ADWB as a biobank and cohort data platform), followed by Q&A sessions and invitation to provide feedback and collaborate on further improving the EPND Hub.
2. Videos have been prepared to present an overview of different types of workflows, to showcase the respective use cases from the perspectives of a researcher and of a data provider / cohort owner.
3. Videos are made publicly available as guidelines/tutorials for EPND platform users on the Vimeo platform via links in this report and via the EPND website <https://epnd.org>.
4. Detailed descriptions of individual access scenarios are provided in the Results section below and summarised in the Discussion of this report.

Results

In this part we document the individual workflows designed by EPND for the sample and data access requests for the following scenarios:

1. Sample Access Request (SAR)
2. Data Access Request (DAR)
3. Data Access Request (DAR) via ADWB
4. Data Access Request (DAR) via ADWB using Federated and Distributed data Sharing Appliance (FDSA)
5. Data Access Request (DAR) via a federated node (using emails)
6. Data Access Request (DAR) via a federated node using FDSA, integrated with node's resource entitlement management system (REMS).

As the final step of a successful request workflow, the resources can be accessed. EPND supports various access modes, depending on the access conditions of a specific resource and on their provider's infrastructure. In general, the following data provisioning options (access types) are possible:

- Downloading
- Data delivery and direct access in ADWB workspace for viewing and analysis
- Remote access to a federated node via FDSA
- Node-specific access (e.g., direct access through a node's local secure processing environment)

A summary and comparison of the scenarios is provided in the Discussion section.

For more details on the access to ND resources and about other functionalities of the EPND platform please refer to:

- Materials and video recordings for this D1.6 deliverable available using the links embedded in the specific scenarios below
- Tutorials for EPND platform users available at EPND websites
 - Discover | EPND: <https://discover.epnd.org/catalogue/user-manual>
 - EPND Hub FAQs | EPND: <https://epnd.org/cohort-admin-faqs>

I. Sample Access Request (SAR)

In the SAR process (see an overview in Fig.2) the user discovers the biosamples advertised via the EPND Hub, explores their details, and applies for samples from their providers. The Expressions of Interest (EOI) step serves as a lightweight precursor to formal sample request process which typically requires more detailed negotiations and legal agreements. EOI can be used by researchers to declare their interest in the resources and get additional information, on top of what is publicly available. The process can be defined individually per resource by its owner, and is generally meant to provide enough information to identified researchers to allow them to understand fitness-for-purpose and availability of the samples, to decide whether a formal SAR is worthwhile.

The extra information about the samples is hosted at the EPND Hub and becomes available to users only upon approval of the EOI. The samples themselves are stored at biobanks and managed by their owners. The actual access/delivery process is arranged directly between the applicant and those institutions.

The SAR demonstration video showcases three main steps of the biosample access workflow: discovery, EOI, and approval and enabling the extended access, which can be followed by a formal SAR submission. The personas involved in the process are the researcher (user) and the sample provider.

1) Sample Access Request

For the demo of this use case, the "*Luxembourg Parkinson's Study*" sample collection is used as an example of a cohort surfacing additional details about their sample collections via the EPND Hub. See the video demo using this [link](#) and the corresponding description of the access procedure below.

1. Discovery

- a. **Visit EPND:** Researcher connects to <https://epnd.org> and selects the EPND Hub (or connect directly to <https://discover.epnd.org>)
- b. **Browse public catalogue:** Researcher opens the EPND catalogue and goes to the "Biosamples collections" tab
- c. **Filter and refine:** Researcher discovers biosample collections using filters and/or text search (in the demo: the "Luxembourg Parkinson's Study")
- d. **Explore biocollection (limited details):** Researcher consults the overview of the study and a summary of the biosample collection. To access further information, the researcher needs to log in or register

2. Expression of interest (EOI)

- a. **Register & login:** Researcher logs in their EPND account (or creates one)

- b. **Explore biocollection (more details):** Researcher can consult more detailed information about the selected resources
- c. **Express interest in biosamples:** Researcher decides to express their interest in the resource and request additional information about the samples; they fill in the EOI (defined by the cohort owner) and submit it
- d. **Confirmation:** Researcher receives an email to confirm that their EOI has been successfully submitted; they can consult the status of their request online

3. Approval and access notification

- a. **EOI arrival notification:** Sample provider is notified about a new EOI by email
- b. **EOI review and approval:** Sample Provider reviews the EOI according to their internal procedures and policies; in case of a positive decision, they approve the EOI
- c. **EOI response:** Researcher is informed about the EOI decision; they can check the status of their request online
- d. **Extended exploration of the biocollection:** Researcher can access extended information about the resource (depending on each resource and provider; in principle it should allow the user to understand fitness-for-purpose and availability of specific samples).

4. SAR process

- a. **Submit SAR:** Upon studying extended info, the researcher can decide to follow up with a formal SAR process. They select “Request samples”, fill in the form and submit to initiate the process and contact directly the sample provider to arrange together the details of the order and a bilateral legal contract.

II. Data Access Request (DAR)

In the DAR process (see Fig.1) the user discovers the dataset advertised via the EPND Hub, explores their details through metadata, and applies for data access to a relevant data provider. The EPND Hub (specifically: its Brokerage Service) is the common starting point for the application process, and it allows tracking the status of submitted requests. Nonetheless, the application forms, their delivery to the data providers and review/approval procedure, as well as data provisioning processes can differ amongst the data providers and are frequently resource specific. Below, a number of different use cases are demonstrated.

The DAR demonstrations showcase the main steps of all dataset access workflows: discovery, submission of DAR, approval of the request and data access. The personas involved are the researcher (user) and the data provider.

1) Data Access Request within EPND

In the basic scenario, a dataset is hosted in a cloud-based repository (the cloud provider's data centre is located in the EU) offered by the EPND Hub. For this use case, EPND provides a DAR mechanism relying on request submission through an online form, and request handling mechanism in ADWB administrative view for data providers. Data provisioning is done by transferring data to the user's ADWB workspace. In the near future, a workflow completely contained within the EPND's Brokerage Service – with request handling in EPND administrative panel for data providers – will be in place.

For this case, an example of "ATN Case Study" dataset, generated and managed jointly by the Partners in the EPND project, is described below and can be viewed using this [link](#) to access a video demonstration.

1. Discovery and requesting access

- a. Researcher visits EPND catalogue and logs in
- b. Researcher finds and explores info about ATN dataset
- c. Researcher initiates DAR form by selecting "Request access" button and fills in the request form
- d. As the ATN study dataset is cloud-hosted via the EPND Hub and accessible through an ADWB workspace, the researcher must indicate their workspace in ADWB platform where the data will be provided upon request approval. If they don't yet have a workspace, they can request creating a new one for this dataset upon acceptance of the request.
- e. Researcher submits the request; they can track its status in the "My Requests" tab of EPND portal

2. Request review

- a. The data providers receive the request via an email

- b. They review the request in ADWB administrative panel, and make a decision about the access

3. Data access

- a. The status of the researcher's request changes to "Approved"
- b. Researcher selects "Go to the request" button and is redirected to their request in the ADWB
- c. Researcher selects "Transfer" button to transfer the requested dataset to their ADWB workspace

2) Data Access Request via ADWB

In this scenario, a dataset is syndicated from ADWB (<https://discover.alzheimersdata.org>), a sister platform of EPND, governed by the AD Data Initiative. The ADWB focuses on Alzheimer's Disease (AD) and related dementias data, and enables its resources to EPND users. Specifically, AD Data Initiative offers centralized cloud-based data hosting to data owners, and provides a data access request process and data provisioning system through ADWB and its private, secure workspaces.

The EPND Data Brokerage Service is tightly integrated with the ADWB system, allowing the data users to login to both with the same account (single sign-on mechanism), discover and apply for data from EPND, and have them delivered to an ADWB workspace.

A detailed example of this workflow for "GERAS" study data highlights the process for submitting a request for access to analyze the dataset which is hosted on the cloud by the AD Data Initiative and accessible via the ADWB; see this [link](#) for a video demonstration.

1. Discovery and requesting access

- a. Researcher visits EPND catalogue and logs in
- b. Researcher finds and explores info about GERAS dataset, a syndicated catalogue entry that is published by and accessible via ADWB
- c. Researcher initiates data access request form by selecting "Request access" button and fills in the request form
- d. As the dataset is hosted by the AD Data Initiative and accessible via ADWB, the researcher must select the ADWB workspace where the data will be made available for analysis when the request has been approved. If the researcher doesn't have an existing workspace, he/she can submit a request for a new workspace.
- e. Researcher submits the request; they can track its status in the "My Requests" tab of the EPND Hub

2. Request review

- a. The data provider is notified about a new request; they can review and approve the application through their administrative panel in ADWB. They can also configure “Auto approval” mechanism to accept the request automatically.

3. Data access

- a. The status of the researcher’s request changes to “Approved”
- b. Researcher selects “Go to the request” button and is redirected to their request in the ADWB
- c. Researcher selects “Transfer” button to transfer the requested dataset to their ADWB workspace

3) Data Access Request via ADWB using FDSA

In this scenario, the metadata of a dataset is also in ADWB platform, but the data is hosted at a federated node associated with ADWB and integrated with it through FDSA (<https://community.addi.ad-datainitiative.org/fdsa>). The FDSA provides its own data access handling mechanism and data provisioning system through ADWB, its in-built workspaces and the Query Builder (QB) tool.

The EPND Data Brokerage Service is tightly integrated with the ADWB system, allowing the data users to login to both with the same account (single sign-on mechanism), discover and apply for data from EPND, and have them delivered to the ADWB workspace.

For this workflow, a detailed example of “*MindAD*” dataset access request is described below and demonstrated in a video accessible under this [link](#).

1. Discovery and requesting access

- a. Researcher visits EPND catalogue and logs in
- b. Researcher finds and explores info about MindAD dataset that is published and accessible by ADWB
- c. Researcher initiates data access request form by selecting “Request access” button and fills in the request form
- d. Since the dataset is associated with ADWB, the researcher must indicate their ADWB workspace from which they will perform the data analysis when approval has been granted. If the researcher doesn’t have an existing workspace, he/she can submit a request for a new workspace.
- e. Researcher submits the request; they can track its status in the “My Requests” tab of the EPND Hub

2. Request review

- a. The data provider is notified about a new request, which has been forwarded to their federated node. They can review and approve the application through the administrative panel in their FDSA. They can also configure the “Auto approval” mechanism in they choose to accept the request automatically.

3. Data access

- a. The status of the researcher's request changes to "Approved"
- b. Researcher selects "Go to the request" button and is redirected to their request in the ADWB
- c. The researcher is provided with appropriate instructions to remote query the data via "Query Builder" tool within ADWB workspace.

4) Data Access Request via a federated node using email

In this scenario, a dataset is hosted at a federated node associated with EPND. The federated node has their established data access procedures relying on email communication with the applicant, which they decide to maintain, without implementing additional mechanisms or technical integrations.

The EPND Brokerage Service supports an email-based access request process by implementing basic online forms to collect the minimum information about the applicant and sending the email message from the EPND platform to the node on behalf of the applicant. Further communication and necessary negotiations are executed directly between the federated node and the applicant. Data provisioning is ensured by the node according to their standard established procedures (usually a direct data download).

To demo this workflow, the "*DZNE – Longitudinal Cognitive Impairment and Dementia Study*" dataset is used as an example of a cohort interested in making their locally-hosted data requestable via the EPND Hub. More details are described below and also via a video demonstration accessible using this [link](#).

1. Discovery and requesting access

- a. Researcher visits EPND catalogue and logs in
- b. Researcher finds and explores info about DZNE dataset
- c. Researcher initiates data access request form by selecting "Contact owner" button and fills in the contact form
- d. Researcher sends the message. They receive an email confirmation, and a promise to be contacted back for further steps of the process.

2. Request review

- a. EPND Study Management team receives an email notification about the request and reviews it.
- b. If any significant information is missing, they can contact the researcher by email to complete it.
- c. Once the request is sufficiently complete, the EPND Study Management team forwards it to the relevant data provider.
- d. The data provider receives the request. They contact the researcher by email to arrange the details of the request, data provisioning and a legal contract, if needed.

3. Data access

- a. Data provider prepares the data and makes them available for download. They share the download URL with the researcher by email.

5) Data Access Request via a federated node using FDSA integrated with node's internal resource entitlement management system (REMS)

In this scenario, a dataset is hosted at a federated node associated with EPND. The node has its established data access procedures relying on an internal resource entitlement management system (REMS, <https://github.com/CSCfi/remis>). At the federated node, REMS is used to collect incoming requests, coordinate reviews, track status, communicate with applicants, and register access decisions. REMS can also integrate with the node's user management system (e.g., Keycloak) and data information system (e.g. DAISY [Becker R, et al. DAISY: A Data Information System for accountability under the GDPR. <https://doi.org/10.1093/gigascience/giz140>]) to ensure full control and accountability in line with General Data Protection Regulation (GDPR) requirements. Thus, the node requires that all requests, including those originating from external data catalogues such as EPND, are routed to the existing data management mechanisms.

The EPND Brokerage Service facilitates integration with a node's internal systems via a FDSA. The FDSA, in addition to its access request handling functions, can act as an intermediary by forwarding incoming requests from the catalogue to internal services (using webhooks), collecting and returning their decisions back to the EPND Hub. For successful integration of EPND and local REMS, the incoming requests must comply with REMS' custom access request forms and include the user's ID as defined in the node's user management system. Data provisioning is handled by the federated node, following established procedures (which may include institutional secure processing environments or direct downloads), or via the FDSA (leveraging ADWB's FAIR Data Services, its built-in workspaces, and the Query Builder tool for remote access) — see Fig. 3.

This scenario is currently being implemented at the EPND Hub, and will become available to users by the end of 2025. EPND users will then be able to submit their requests through the EPND platform to the federated node, and eventually receive the decisions in “My Requests” tab, while their request will be processed by the node's internal systems. In the meantime, they might be contacted directly by the node's data stewards (e.g., via REMS or email) to provide additional info, or to sign the legal contract.

An envisoned scenario of this workflow for “*Luxembourg Parkinson Study*” dataset as an example of a cohort with data hosted by University of Luxembourg (UNILU), making study data requestable via the EPND Hub is described below.

1. Discovery and requesting access

- a. Researcher visits the EPND catalogue and logs in
- b. Researcher finds and explores information about “*Luxembourg Parkinson Study*” dataset
- c. Researcher initiates data access request form by selecting the “Request access” button and fills in the request form
- d. As the dataset is managed by a federated node, whose systems rely on its own user identity management, the researcher must connect to an account at the node before submitting a request. The researcher is redirected to a node’s service (Keycloak) where they can log in using their existing account (at UNILU, or at other scientific institution participating in LifeScience RI via eduGAIN network, or ORCID) or create a new account.
- e. After successful login, the researcher is redirected back to EPND and can submit the request; they can track its status in the “My Requests” tab of the EPND portal.

2. Request review

- a. The data provider is notified of the new request, which is automatically forwarded via FDSA to their federated node’s REMS system.
- b. Data stewards review the application through the administrative panel in REMS. If any information is missing, they contact the researcher (by REMS or email) to complete it.
- c. Once the request is complete, data stewards contact the relevant data access committee to review and approve the request.
- d. Data stewards confirm the access decision in REMS, the decision is automatically propagated via FDSA to the EPND portal.

3. Data access

- a. The status of the researcher’s request changes to “Approved”
- b. The application response provides details on how the data can be accessed.
- c. Depending on the specific request case and the necessity for data minimisation, the dataset is either directly available for remote access via the FDSA and the ADWB QB tool, or a dedicated minimised subset is prepared by the data provider and made available in an internal secure processing environment.

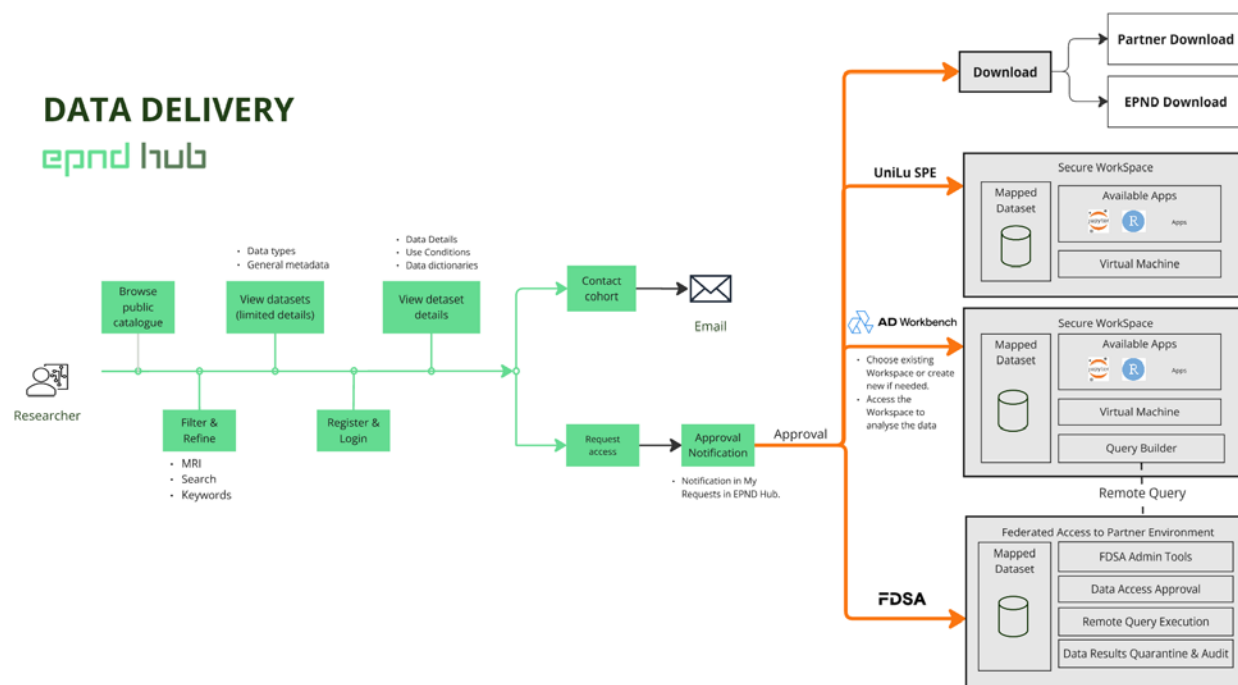


Figure 3 Data access request ("Luxembourg Parkinson Study" example)

Discussion

The successful demonstrations provided by this Deliverable validate the workability of sample and data access request service through the EPND Hub for a number of different scenarios, taking into account diverse data-storage, technical capabilities, and access conditions. Summary characteristics of the core request workflows is shown in Table 1 below.

Practical experience with different EPND use cases so far has allowed us to formulate the following observations:

- **Timeline variations** in request processing are significant and depend on request complexity and institutional review processes. Certain cohorts making their data requestable via access request forms in the EPND Hub have opted for an automated approval process, which can greatly reduce the time-to-access, in some cases as quickly as 15mins. On the other end of the scale, some approvals require a decision by the relevant Data Access Committee who only assembles in fixed time intervals, e.g., every several weeks.
- **Versatility**: Some federated nodes may support **multiple access methods** depending on their technical capabilities and resource specific constraints, e.g., download of some datasets and remote access to others, depending on the resource's access conditions established by their owners and/or funders. Access request forms can be individually tailored to the needs of the specific resources or their owners.
- **Interoperability**: Some federated nodes might be involved in **multiple data sharing networks**, one of them being EPND. A local storage, resource management system, and data provisioning mechanisms allow them to make their datasets available through multiple catalogues and coherently managed at source, at the cost of higher technical involvement of people and systems. For those nodes, integrating their systems with EPND is a way of increasing their visibility among researchers in ND field who use the EPND platform as the main point for data discovery.
- **Convenience**: Conversely, for data owners with technical constraints or low numbers of data resources, the complete offer of EPND (data hosting, access, and provisioning based on the governance requirements of the provider) might be a straightforward solution to enable them to share their resources and facilitate otherwise manual and tiresome processes. As a result, the EPND Hub might be able to offer **unique resources**, not (or hardly) available through other means and networks, that will be viable data sharing solutions for data providers with a variety of needs and requirements.

Table 1. EPND Access Request Methods Comparison

Workflow	EOI + SAR	DAR (EPND)	DAR (EPND + ADWB)	DAR via ADWB	DAR via ADWB using FDSA	DAR via Federated Node (email)	DAR via Federated Node using FDSA
Aspect							
Resource Type	Biological samples	Datasets	Datasets	Datasets	Datasets	Datasets	Datasets
Resource Location	stored at biobanks or by sample owners	centralized in EPND (cloud-storage, Netherlands)	centralized in EPND (cloud-storage, Netherlands)	centralized in ADWB (cloud storage, Netherlands)	stored at federated node	stored at federated node	stored at federated node
Prerequisites for request	EPND account	EPND account, email communication	EPND account, ADWB workspace, email communication	EPND account, ADWB workspace (existing or new)	EPND account, ADWB workspace (existing or new)	EPND account, email communication	EPND account, node-specific authentication
Process Steps for Request	1. Discovery 2. EOI request form 3. EOI approval 4. Extended info access 5. SAR submission 6. SAR negotiations and bilateral contract 7. Sample provision	1. Discovery 2. Request form 3. Approval 4. Access provision	1. Discovery 2. Request form 3. Approval 4. Access provision	1. Discovery 2. Request form 3. Approval 4. Access provision	1. Discovery 2. Request form 3. FDSA routing 4. Approval 5. Access provision	1. Discovery 2. Email request form 3. Approval 4. Access provision	1. Discovery 2. Request form 3. FDSA routing 4. REMS routing 5. Approval 6. Access provision
Request Approval Process	Two-stage approval by sample owner: - EOI approval in EPND Hub, decision registered at EPND - Formal SAR negotiation and approval by email	Single approval upon review by data provider in EPND Hub, decision registered in EPND	Single approval upon review by data provider in ADWB or auto-approval, decision registered at ADWB and EPND	Single approval upon review by data provider in ADWB or auto-approval, decision registered at ADWB and EPND	Single approval upon DAR review by data provider in FDSA administrative panel or auto-approval in FDSA	Approval upon DAR negotiation via email exchange with the data provider at the node and review	Single approval upon DAR review by data provider in REMS administrative panel, or semi(automated) in REMS
Request Tracking	Tracking EOI by EPND Hub, external tracking for SAR	EPND Hub	EPND Hub	EPND Hub and ADWB	EPND Hub, ADWB and FDSA	External tracking	EPND Hub, FDSA, and REMS.
Request Timeline (Typical)	EOI: typically 1-2 weeks SAR: variable, but could be 1-3 months	DAR: variable, can range from minutes to up to 2 months	DAR: variable, can range from minutes to up to 2 months	variable, can range from minutes to up to 2 months	variable, can range from minutes to up to 2 months	2-4 weeks	variable, can range from minutes to up to 2 months
Legal Framework	Bilateral MTA/contract	Data Use Agreements with researchers are based on the data governance requirements of providers	Data Use Agreements with researchers are based on the data governance requirements of providers	Data Use Agreements with researchers are based on the data governance requirements of providers	Data Use Agreements with researchers are based on the data governance requirements of providers	Node- or data-specific agreement	Node- or data-specific agreement
Access Method	Extended data are accessible in EPND; Physical sample transfer	Data copy to workspace	Data copy to workspace	Data copy to workspace	Data copy to workspace, or remote access via FDSA in workspace	Download or node-specific	Remote access via FDSA in workspace, download, or node specific
Access Location	Samples shipped to researcher	Remote access to data in ADWB	Remote access to data in ADWB	Remote access to data in ADWB	Remote access to data in ADWB or at the node	Data downloaded locally or remote access at the node	Data downloaded locally, or remote access at the node
Site's Technical Integration	Minimal (online forms, email-based)	Minimal (online forms)	Minimal (online forms)	Minimal (online forms)	FDSA installation	Minimal (email-based)	FDSA installation and integration with local REMS

Automation Level	Medium (automated EOI, manual SAR process)	High (automated DAR)	High (automated DAR)	High (automated DAR)	High (automated DAR)	Low (manual DAR)	High (automated DAR)
Scenario Best For	- Physical samples - Complex negotiations - Special handling requirements	- ND-scoped data - Cloud storage and analysis - Standard data access (not syndicated from another platform)	- ND-scoped data - Cloud storage and analysis - Standard data access (via ADWB only)	- AD-scoped data- Cloud storage and analysis - Standard data access (via ADWB only)	- AD-scoped data - Local storage - Compliance needs - Standard and federated data access (from multiple origins, not only via ADWB)	- ND-scoped data - Local storage - Compliance needs - Legacy systems without DAR process automation - Custom requests	- ND-scoped data - Local storage - Compliance needs - Systems with DAR process automation - Standard and federated data access (from multiple origins, not only via ADWB)
Example resource	"Luxembourg Parkinson's Study"	N/A (coming soon)	"ATN Case Study"	"GERAS Study – EU"	"MindADmini"	"DZNE – Longitudinal Cognitive Impairment and Dementia Study"	"Luxembourg Parkinson's Study" (coming soon)

Conclusions

The EPND platform represents a significant step forward in harmonizing and streamlining access to ND research data and biosample collections. By integrating federated repositories, standardizing metadata, and implementing secure authentication mechanisms, it provides a centralized, efficient, and compliant 'one-stop-shop' data access environment.

The demonstration of sample and data access request service with EPND Hub marks a significant achievement in the EPND project. The demonstration of the six distinct use cases provides a comprehensive view of sample and data access request service capability of the EPND Hub. The integration of EPND, ADWB, and institutional data providers as federated nodes proves the feasibility of scalable data access and request mechanisms across multiple infrastructures. It also highlights the need for flexibility when integrating existing infrastructures to both offer unified user (researcher) experience and ensure consistent request handling processes at data providers, while trying to onboard as many data sources as possible to become an established reliable entry point to the world of neurodegenerative research.

The demonstrated request functionality of the EPND Hub is the cornerstone for further technical developments of the EPND platform. Future efforts will focus on expanding dataset coverage, refining access control mechanisms, and improving metadata interoperability across federated nodes. Potential further technical integration with other existing networks/platforms and their data management systems (such as UNILU's data hosting node with its REMS and Identity and Access Management (IAM) systems), will allow transparent request flow and interoperability across a wider pool of available data resources.

With continuous advancements in security, interoperability, and user experience, the EPND platform is poised to become a leading resource for neurodegenerative research, fostering collaborative data sharing and accelerating scientific breakthroughs that drive progress in the field.

Repository for primary data (if applicable)

Relevant data and sample repositories referenced in EPND Catalogue: <http://discover.epnd.org>