The European Platform For Neurodegenerative Diseases (EPND)

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epnd — European Platform for Neurodegenerative Diseases

Accelerating the discovery of diagnostics and treatments for neurodegenerative diseases by removing barriers to data and sample sharing
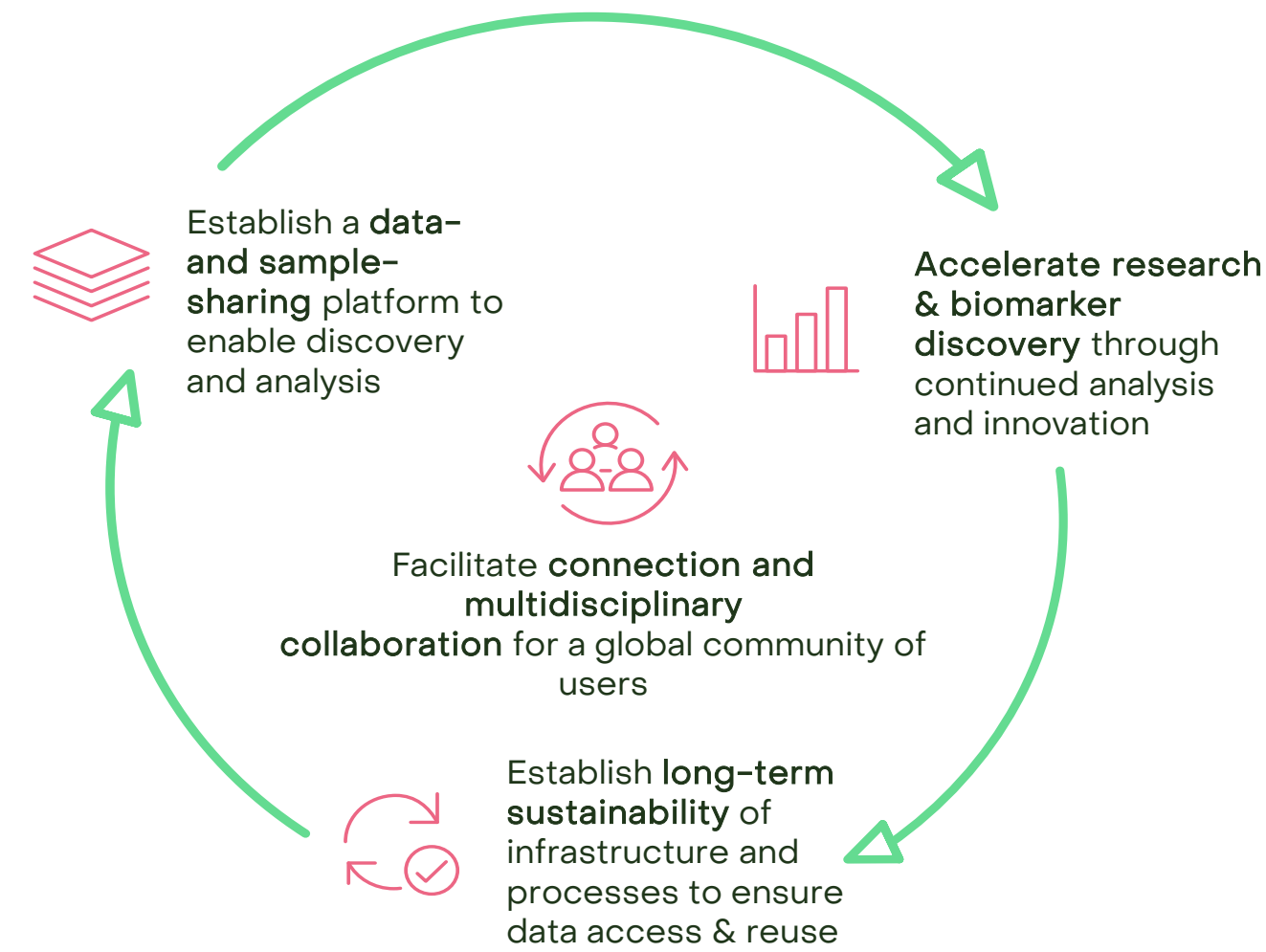

Biomarker discovery, development and validation are reliant on large-scale analyses of high-quality samples and data. Discovery, access and sharing of data and samples are hindered both by silos that limit collaboration, and by complex requirements for secure, legal and ethical sharing. The European Platform for Neurodegenerative diseases (EPND) was launched in November 2021, aiming to address these challenges.

EPND is a public-private partnership funded by the Innovative Medicines Initiative (IMI), a Joint Undertaking between the EU and European pharmaceutical industries. EPND is building a collaborative platform for efficient sample and data sharing, leveraging existing European research infrastructures to accelerate the discovery of biomarkers, new diagnostics and treatments for neurodegenerative diseases.

EPND Objectives

Advancing Research · Supporting Collaboration · Increasing Visibility · Building Capacity · Promoting Sustainability

EPND aims to advance large-scale clinical research efforts to identify & validate biomarkers, accelerating development of innovative diagnostics & treatments for neurodegenerative disease. EPND will:

- Accelerate research & biomarker discovery through continued analysis and innovation
- Facilitate connection and multidisciplinary collaboration for a global community of users
- Establish long-term sustainability of infrastructure and processes to ensure data access & reuse
- Establish a data- and sample-sharing platform to enable discovery and analysis

Project co-Leads and Partners

EPND is a collaborative effort across private and public partners to end neurodegenerative disease, supported by the IMI. The contributions of the 29 following organisations make this work possible:

Maastricht University
Project Co-Coordinator: Pieter Jelle Visser Professor of Molecular Epidemiology of AD, Department of Psychiatry & Neuropsychology

University of Leicester
Project Co-Coordinator: Anthony J. Brookes Professor of Genetics, Department of Genetics & Genome Biology

ucb
Project Co-Leader: Phil Scordis Head of Patient Data Analytics, Data & Translational Sciences

Gates Ventures
Project Co-Leader: Niranjan Bose Managing Director of Health & Life Sciences

AC Immune · Alzheimer Europe · Anthia · BBMRI-ERIC · King's College London · bmd · eatris · Janssen · CTUV · Roche · NOVARTIS · sanofi · Lygature · VUmc VU University Medical Center Amsterdam · SVAR · Takeda · teva · DZNE · IBBL · University of Oxford · Université de Genève · cBmb Medicines Evaluation Board · University Medical Center Groningen · University of Gothenburg · Université du Luxembourg

EPND: Methodology

Key Stakeholder Engagement

Resources & Operating Procedures
- Compliance Best Practices
- Research Resources
- White Papers
- Operating Procedures
- Data Harmonisation

Discovery
- Record-Level Data
- Resource-Level Data
- Sample Discovery
- Samples Access
- Federated Biobanks

Data Analysis & Collaboration
- Analytic Workspaces
- Community Facilitation
- Tools & Infrastructure
- Trainings & Resources
- Data Storage & Access (Federated · Federated)
- Data & Sample Linkages
- Case Studies

Tools to Accelerate Research
- Data Challenges
- Case Studies
- Research Papers
- Novel Findings

Fig. 1. The European Platform for Neurodegenerative Diseases (EPND). EPND users will be able to discover, request access to, and share data and samples from partnering cohorts, supported by resources, standard operating procedures, tools and guidance.

The Alzheimer's Disease Data Initiative (ADDI) AD Workbench powers EPND's technical hub, which will connect European researchers to a global network.

ADDI Alzheimer's Disease Data Initiative

Results: the EPND Cohort Catalogue

67 Neurodegenerative disease research cohorts · **17** European countries · **12** Neurodegenerative disease areas · **159,675** Research participants

Featuring an extensive list of European cohorts across the neurodegenerative disease spectrum, the Cohort Catalogue is a central, open, accessible repository for researchers to discover ongoing studies and search metadata by disease area, biosample availability, imaging and cognitive data, and more.
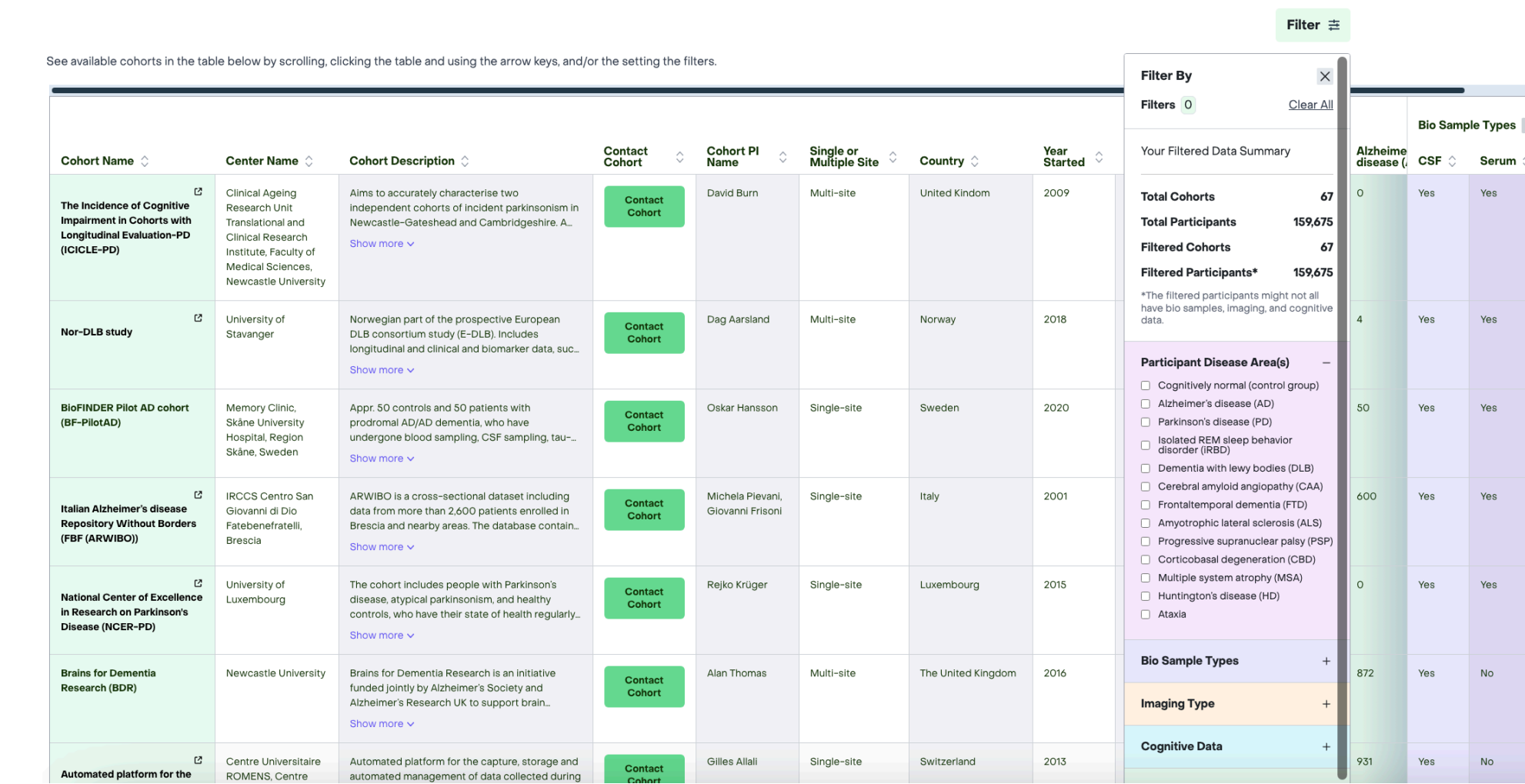

Fig. 2. Screen capture of the EPND Cohort Catalogue. The Cohort Catalogue is an openly-accessible resource allowing researchers to discover information and metadata about European neurodegeneration research cohorts. Image shows the scrollable cohort listing, contact cohort feature, and Catalogue filter tool.

The Catalogue was constructed thanks to information and metadata provided by neurodegeneration research cohorts, with **Rejko Krüger** (PD), **Dag Aarsland** (DLB) and **PJ Visser** (AD) as leads for their respective disease communities.

Current Catalogue features include:

- **Search and Filter tool:** filter cohorts by metadata characteristics
- **Contact Cohort feature:** engage & collaborate with cohorts of interest
- **Self-service dashboard:** manage cohort listings and contact requests
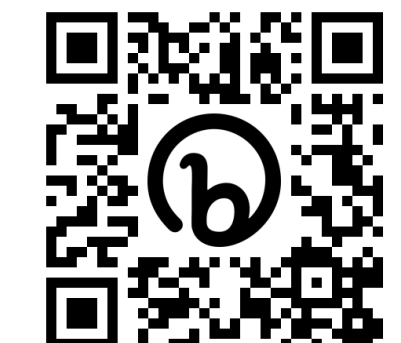
Scan the QR code to discover the Catalogue, and learn how to add your cohort!

Results: Biomarker SOPs

To optimise the quality and standardisation of data and samples in EPND, we are developing common protocols for sample collection and storage, and clinical data collection.
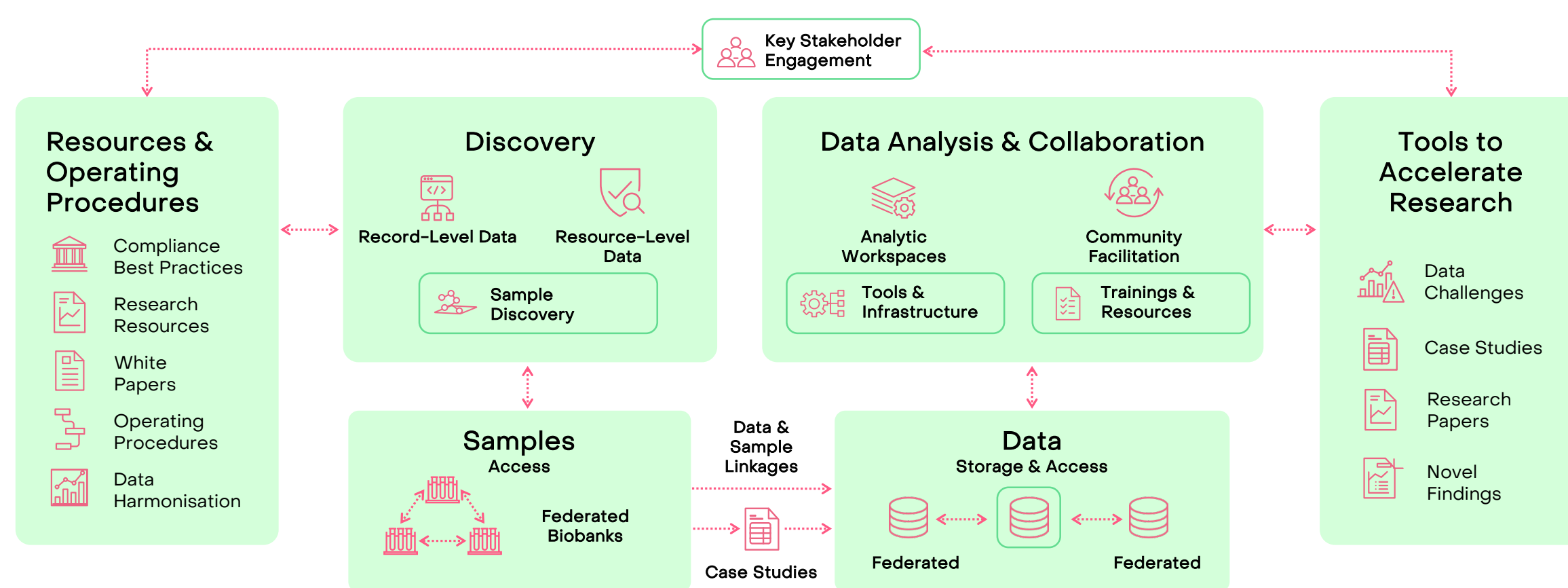
SOP for body materials collection

This SOP updates and harmonises existing SOPs for collection, processing, transfer and storage of the following body materials:

CSF · Serum · PBMCs · Plasma · Urine · Stool · Saliva

Best Practices for biobanking

This guideline was developed following a survey of 7 EPND partner cohorts, after which best practices were compiled on the following areas:

QMS · Biospecimen collection, processing, storage, distribution · BIMS · QC
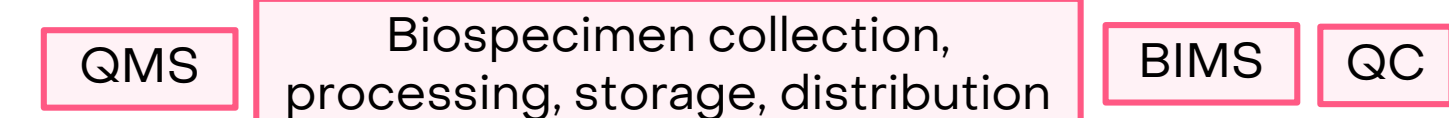
Results: Case Studies

EPND will carry out five biomarker case studies, designed to test the functionalities of the platform, and delivering results that will be integrated back into EPND to benefit the wider research community:

- **Case Study 1:** ATN staging system
- **Case Study 2:** Complement assays
- **Case Study 3:** Microbiome feasibility
- **Case Study 4:** Molecular subtypes validation
- **Case Study 5:** Pilot of full functionality

For Case Studies 1, 2 and 4, EPND has identified 350 plasma & serum samples from healthy individuals, participants with AD, PD or DLB, from the following institutions:

VUmc VU University Medical Center Amsterdam · uni.lu Université du Luxembourg · ace alzheimer center BARCELONA · FN MOTOL · Université de Genève · DZNE · University of Stavanger

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EPND has made concrete advances towards the development of a platform for sample and data sharing, launching a Cohort Catalogue, developing SOPs, and initiating biomarker case studies.

By supporting researchers to discover, access, and reuse data & samples, as part of a scalable infrastructure facilitating global collaboration, EPND aims to be a sustainable solution to support more disruptive research on biomarkers, diagnostics and therapies for neurodegenerative diseases in Europe.

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