

Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD) Prognostic and Natural History Study (PNHS)

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Data source

Human

Other

Administrative details

Administrative details

Data source ID

1000000027

Data source acronym

AMYPAD PNHS

Data holder

[Amsterdam UMC](#)

Data source type

Other

Data source type, other

Research Cohort

Main financial support

European public funding

Care setting

Other

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

<https://amypad.eu/project/amypad-pnhs/>

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Data source regions and languages

Data source countries

Belgium

France

Germany

Greece

Italy

Netherlands

Spain

Sweden

Switzerland

United Kingdom

Data source languages

English

Data source establishment

Data source time span

First collection: 16/12/1986

The date when data started to be collected or extracted.

Publications

Data source publications

[Quantitative amyloid PET in Alzheimer's disease: the AMYPAD prognostic and natural history study](#)

[Recruitment of pre-dementia participants: main enrollment barriers in a longitudinal amyloid-PET study](#)

[The amyloid imaging for the prevention of Alzheimer's disease consortium: A European collaboration with global impact](#)

Data elements collected

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details (other)

Alzheimer's disease

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

No

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

No

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Not Captured

Dispensing of medicines

Not Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

Custom (AMYPAD)

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available?

The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

OMOP

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Captured

Biomarker data vocabulary

Other

Biomarker vocabulary, other

LOINC

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

Yes

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Not Captured

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Diet

Frequency of exercise

Other

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Education level

Ethnicity

Gender

Marital status

Quantitative descriptors

Population Qualitative Data

Population age groups

Adults (46 to < 65 years)

Elderly (\geq 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Data source is a collection of data from different European cohorts of subjects at risk or in preclinical or early stages of Alzheimer's Disease. In all cases, based on consent to participation in the research study, but with different inclusion criteria and sources of recruitment (e.g. memory clinic, advertisement, etc).

Population

Population size

3368

Population by age group

Age group	Population size
Adults (46 to < 65 years)	1323
Elderly (\geq 65 years)	2045
Adults (65 to < 75 years)	1431
Adults (75 to < 85 years)	519

Age group	Population size
Adults (85 years and over)	95

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

0.50

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

[AMYPAD PNHS - Data Access Request](#)

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Event triggering registration

Event triggering registration of a person in the data source

Other

Event triggering registration of a person in the data source, other

Admitted to research cohort

Event triggering de-registration of a person in the data source

Other

Event triggering de-registration of a person in the data source, other

Withdraw of consent to be included in Parent Cohort

Event triggering creation of a record in the data source

Inclusion in Parent Cohort

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

Yes

Linkage description, pre-linked

The current version of the dataset integrates information from 10 Parent Cohorts: ALFA+, AMYPAD DPMS, DELCODE, EMIF-AD (60++ and 90+), EPAD LCS, FACEHBI, F-PACK, Microbiota, and UCL-2010-412

Each participant enrolled in the AMYPAD PNHS study received a unique identifier that was matched by the parent cohort to their original unique identifier.

Linkage Strategy - Deterministic

Linkage is based on unique subject identifier (person_id) and visit identifier (visit_id)

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

ALFA+

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

AMYPAD DPMS

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

DELCODE

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

EMIF-AD 60++

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

EMIF-AD 90+

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

EPAD LCS

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

FACEHBI

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

F-PACK

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

Microbiota

Linkage strategy

Deterministic

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

UCL-2010-412

Linkage strategy

Deterministic

Data management specifications that apply for the data source

Data source refresh

Every 6 months

Informed consent for use of data for research

Other

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

No

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Informed consent, other

Not applicable when project aims aligns with original project description

Data source last refresh

01/06/2023

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

Yes

CDM Mappings

CDM name

OMOP

CDM website

<https://www.ohdsi.org/Data-standardization/>

Data source ETL CDM version

5.4

Data source ETL frequency

6,00 months

Data source ETL status

Completed

Data source ETL specifications (link)

<https://github.com/AMYPAD/ETL-PNHS>