Long-term International Dual-Source Endometriosis and Adenomyosis Registry (LIDEA Registry)

First published: 27/10/2023

Last updated: 02/03/2026

Study Ongoing

Administrative details

EU PAS number

EUPAS107377

Study ID

107378

DARWIN EU® study

No

Study countries

France

Germany

Italy

Spain

United Kingdom

United States

Study description

This prospective registry focuses on people with a confirmed, or presumed diagnosis of the two common chronic gynecological diseases: endometriosis and adenomyosis. Longitudinal data will be collected from eligible study participants directly with the aim to better understand the course of endometriosis and adenomyosis. Specific focus will be applied to pelvic pain and quality of life outcomes under different treatment pathways as prescribed by health care practitioners in real-world clinical practice. The data collected for this registry will further contribute to knowledge generation and accelerate scientific innovation in the scientific community of endometriosis and adenomyosis.

Study status

Ongoing

Research institutions and networks

Institutions

Berlin Center for Epidemiology & Health Research, ZEG Berlin

Germany

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Institution **Laboratory/Research/Testing facility** **ENCePP partner**

Contact details

Study institution contact

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Study contact

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Primary lead investigator

Klaas Heinemann

Primary lead investigator

Study timelines

Date when funding contract was signed

Planned: 08/11/2022

Study start date

Planned: 01/01/2024

Actual: 17/11/2025

Date of final study report

Planned: 29/12/2031

Sources of funding

- No external funding

Regulatory

Was the study required by a regulatory body?

No

Is the study required by a Risk Management Plan (RMP)?

Not applicable

Methodological aspects

Study type

Study type list

Study topic:

Disease /health condition

Human medicinal product

Study type:

Non-interventional study

Scope of the study:

Disease epidemiology

Drug utilisation

Effectiveness study (incl. comparative)

Evaluation of patient-reported outcomes

Healthcare resource utilisation

Data collection methods:

Primary data collection

Main study objective:

Epidemiological assessment of the course of pelvic pain and the development of endometriosis and/or adenomyosis./Examine treatment pathways and outcomes of pelvic pain with or without specific diagnoses (e.g. endometriosis, adenomyosis) including health economic outcomes./Examine the relationship between changes in patient-reported outcome (PRO) measures and healthcare resources utilization.

Study Design

Non-interventional study design

Other

Population studied

Age groups

- Adolescents (12 to < 18 years)
- Adults (18 to < 46 years)
- Adults (46 to < 65 years)
- Adults (65 to < 75 years)
- Adults (75 to < 85 years)
- Adults (85 years and over)

Estimated number of subjects

14.000

Study design details

Outcomes

See above, Effect of therapies on pain/Effect of therapies on bleeding/Identification of therapeutic gaps/Situational analysis of treatment across geographies and countries/Operative vs. medical treatment/National preferences regarding diagnostic and therapeutic pathways, physician perception of successful disease management/Impact of disease and different treatments on work, partnership etc.

Data analysis plan

ZEG Berlin will develop a written Statistical Analysis Plan (SAP) covering the annual progress reporting according to the Study Protocol. A draft SAP including TLFs (tables, listings, figures) will be provided by ZEG Berlin to the Scientific Governance Board for review within 6 months of the study start. The SAP will describe the analysis variable derivation and statistical methodology of planned study reports.

Data management

ENCePP Seal

The use of the ENCePP Seal has been discontinued since February 2025. The ENCePP Seal fields are retained in the display mode for transparency but are no longer maintained.

Data sources

Data sources (types)

Disease registry

Other

Use of a Common Data Model (CDM)

CDM mapping

No

Data quality specifications

Check conformance

Unknown

Check completeness

Unknown

Check stability

Unknown

Check logical consistency

Unknown

Data characterisation

Data characterisation conducted

No