

# 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

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### Study ID

107378

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### DARWIN EU® study

No

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### Study countries

 France

 Germany

 Italy

 Spain

 United Kingdom

 United States

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## 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.

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## Study status

Ongoing

## Research institutions and networks

### Institutions

**Berlin Center for Epidemiology & Health Research,  
ZEG Berlin**

 Germany

**First published:** 06/08/2019

**Last updated:** 23/06/2026

**Institution**

**Laboratory/Research/Testing facility**

**ENCePP partner**

# Contact details

## Study institution contact

Pauline De Corte p.de-corte@zeg-berlin.de

Study contact

[p.de-corte@zeg-berlin.de](mailto:p.de-corte@zeg-berlin.de)

## Primary lead investigator

Klaas Heinemann

Primary lead investigator

# Study timelines

## Date when funding contract was signed

Planned: 08/11/2022

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## Study start date

Planned: 01/01/2024

Actual: 17/11/2025

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## 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

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**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

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**Study type:**

Non-interventional study

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**Scope of the study:**

Disease epidemiology

Drug utilisation

Effectiveness study (incl. comparative)

Evaluation of patient-reported outcomes

Healthcare resource utilisation

**Data collection methods:**

**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)

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**Estimated number of subjects**

14000

## 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.

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## **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

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### **Check completeness**

Unknown

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### **Check stability**

Unknown

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### **Check logical consistency**

Unknown

## Data characterisation

### **Data characterisation conducted**

No