

# Project Protocol

## Endometriosis: International Care Standards and Healthcare Reality in Vienna

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**Duration:** Q1 2026 to Q3 2026 (8 PM)

**Language:** English (with German summary)

### Background:

Endometriosis is one of the most common gynaecological conditions affecting people of reproductive age [1]. In addition to women, trans men and non-binary individuals may also be affected; the terms “individuals” and “patients” are used throughout to reflect this diversity.

Endometriosis is a benign, chronic inflammatory condition characterised by the presence of endometrium-like tissue (endometriotic lesions) outside the uterus [2, 3]. The condition primarily affects the abdominal cavity, the ovaries, the fallopian tubes, and the bladder [2]. The severity of symptoms can vary considerably, and not all affected individuals experience symptoms. The type and intensity of symptoms depend, amongst other factors, on the location and degree of inflammation of the endometriotic lesions [4]. The most common symptoms include severe pain, particularly during menstruation, pain during sexual intercourse, and infertility; these are frequently associated with a reduced quality of life and psychosocial impairment [3, 4]. Data from Austria indicate that nearly all individuals with a diagnosis of endometriosis suffer from menstrual pain, with 81% reporting very severe, severe, or moderate pain. Approximately 61% report additional pain symptoms related to endometriosis [1]. A complete cure of the condition is currently not possible, as its exact aetiology remains unknown [2, 4]. Therapeutic measures aim to alleviate symptoms and improve quality of life. The choice of treatment is guided by the individual circumstances of the affected person, in particular whether pain, an unfulfilled desire to have children, or both are the primary concern. Possible treatment options include pharmacological pain management, hormonal treatments, and surgical interventions, which may be applied individually or in combination [4].

Despite being one of the most common chronic conditions affecting people of reproductive age, many patients with endometriosis report that their pain and symptoms are not taken seriously by healthcare professionals or are dismissed as “normal.” This experience of not being heard contributes to emotional distress, loss of trust, and delayed diagnoses [5, 6].

In Austria, 6.4% of menstruating individuals aged 14 to 60 are estimated to be affected by endometriosis, approximately two-thirds (67%) of whom are pre-menopausal. A further 4.4% are suspected of having the condition [1]. The true number is likely underestimated due to the high number of undiagnosed cases, with estimates suggesting that up to 300.000 individuals may be affected [7]. The evidence base on endometriosis in Austria is generally very limited, with little representative data available on risk factors or the state of healthcare provision [8]. Furthermore, nearly one-third (31.3%) of potentially affected individuals have no prior knowledge of endometriosis as a condition. The time to diagnosis in Austria currently averages 6.6 years [1].

### Project aims:

This report aims to systematically identify and synthesise current international guideline recommendations and care pathways for the diagnosis and treatment of endometriosis, to derive evidence-based recommendations, and to assess the extent to which these recommendations are implemented within the current healthcare system in Vienna. The interdisciplinary care structure will be described, and those aspects of care that can be improved from the perspective of patients and healthcare providers will be identified.

### Non-Objectives:

- The project does not aim to systematically evaluate treatment methods.
- The project does not aim to conduct a health economic analysis.

## Research question:

**RQ 1:** Which evidence-based diagnostic and therapeutic recommendations for endometriosis are contained in current international guidelines, how are these classified regarding the level of evidence and strength of recommendation, which high-evidence interventions can be derived for clinical practice, and which organisational structures and care pathways are recommended internationally?

**RQ 2:** What is the current care structure in Vienna, and which gaps in care and unmet needs do patients and healthcare providers identify in practice?

**RQ 3:** To what extent does current care practice in Vienna align with international guideline recommendations and recommendations for care pathways?

## Methods:

**RQ 1:** To address the first research question, a hand search for international guidelines on the diagnosis and treatment of endometriosis will be conducted, supplemented by a targeted hand search for recommendations on care pathways and models. The guideline synopsis published in the Australian Journal of General Practice (AJGP) [9] will serve as a starting point, which will be updated and, where appropriate, expanded to include additional selected guidelines. The selection of relevant publications will be based on pre-defined inclusion and exclusion criteria. All methodological steps, including literature selection, data extraction, and quality appraisal, will be carried out according to the four-eyes principle: one author will take primary responsibility for processing, whilst a second author will review and validate the results. Following completion of the literature search, the identified outcomes will be systematically extracted and synthesised. These will be used to map the key diagnostic and treatment pathways. Because the included guidelines use varying systems for levels of evidence and grades of recommendation (LoE/GoR), an attempt should be made to convert all recommendations into a uniform scale to facilitate comparability. This will enable a consistent synthesis and a clear presentation of high-evidence recommendations.

**RQ 2:** To capture the reality of endometriosis care and any existing gaps in Vienna, a hand search for data on existing care structures will first be conducted. The comparative analysis of the organisation of endometriosis care in five high-income countries by Leroy et al. (2025) [10] will serve as the basis for this. In addition, the perspectives of affected patients and healthcare providers are also assessed.

The hand search aims to provide a comprehensive overview of existing care structures, services offered, and their accessibility.

To capture the perspectives of patients and healthcare providers, a standardised survey will be conducted in Vienna. The survey instrument combines open-ended questions with pre-defined response categories to collect both quantitative and qualitative data.

The patient survey examines experiences with the diagnostic and therapeutic process, perceived strengths and challenges of care, patients' needs and expectations regarding healthcare provision, and satisfaction with current treatment.

The healthcare provider survey focuses on the implementation of guideline recommendations in clinical practice, existing barriers, the organisation of interdisciplinary care structures, and an assessment of the feasibility of implementing existing guideline recommendations from the AJGP guideline synopsis within the Austrian healthcare context.

**RQ 3:** The findings from all three methodological components will be synthesised and systematically compared. The international care standards identified in RQ 1 will serve as a reference framework. These will then be compared with the findings from RQ 2 to analyse the extent to which the recommended standards are actually being implemented in healthcare practice in Vienna.

The mixed-methods approach is intended to enable the identification of specific areas for action to optimise endometriosis care in Vienna, considering both evidence-based guideline recommendations and the perspectives of healthcare providers and patients.

## Inclusion criteria (PICOS Table for the Synopsis of International Guidelines and Care Pathways):

|               |                                                                                                                                                                                                                                                                                                                                                                                                  |
|---------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Population    | Individuals with a confirmed or suspected diagnosis of endometriosis<br>Healthcare providers (e.g. gynaecologists, general practitioners, nursing staff, therapists) in the context of endometriosis care                                                                                                                                                                                        |
| Intervention  | Care in accordance with evidence-based guidelines and recommended treatment pathways                                                                                                                                                                                                                                                                                                             |
| Kontrolle     | —                                                                                                                                                                                                                                                                                                                                                                                                |
| Outcomes      | <ul style="list-style-type: none"> <li>Current evidence-based guideline recommendations for the diagnosis and treatment of endometriosis</li> <li>Indications and fields of application, Level of Evidence (LoE) and Grade of Recommendation (GoR)</li> <li>Care structures and organisational models</li> <li>Recommendations for care pathways and their implementation in practice</li> </ul> |
| Studiendesign | Evidence-based guidelines and recommendations on care pathways                                                                                                                                                                                                                                                                                                                                   |
| (Länder)      | Selected western countries with comparable healthcare systems                                                                                                                                                                                                                                                                                                                                    |
| Sprachen      | English, German                                                                                                                                                                                                                                                                                                                                                                                  |

## Timetable:

| Period     | Tasks                                                                                                    |
|------------|----------------------------------------------------------------------------------------------------------|
| Q1 2026    | Scoping and finalisation of the project protocol                                                         |
| Q1 2026    | <ul style="list-style-type: none"> <li>Manual literature search</li> <li>Literature selection</li> </ul> |
| Q1/Q2 2026 | Data extraction and quality appraisal; survey data collection                                            |
| Q3 2026    | Analysis and evaluation of surveys                                                                       |
| Q3 2026    | Writing                                                                                                  |
| Q3 2026    | Internal and external review                                                                             |
| Q3 2026    | Layout & publication                                                                                     |

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