# QS ENDO Pilot – A Study by the Stiftung Endometrioseforschung (SEF) on the Quality of Care Provided to Patients with Endometriosis in Certified Endometriosis Centers in the DACH Region

# QS ENDO Pilot – eine Studie der Stiftung Endometrioseforschung (SEF) zur Versorgungsqualität von Patientinnen mit Endometriose in den zertifizierten Endometriosezentren der DACH-Region

OPEN ACCESS

Authors

Ivo Meinhold-Heerlein[1*], Magdalena Zeppernick[1*], Monika Martina Wölfler[2], Elisabeth Janschek[3], Sebastian Bornemann[4], Laura Holtmann[4], Frank Oehmke[1], Darius Salehin[6], Chi Mi Scheible[6], Iris Brandes[5], Sigrid Vingerhagen-Pethick[7], Claus-Peter Cornelius[17], Alexander Boosz[8], Bernhard Krämer[9], Martin Sillem[10,11], Klaus Bühler†[10,12,13,14], Jörg Keckstein[10,15,16], Karl-Werner Schweppe[10], Felix Zeppernick[1], for the AG QS Endo of the Stiftung Endometrioseforschung (SEF)[**]

Affiliations

1 Zentrum für Frauenheilkunde und Geburtshilfe der Justus Liebig-Universität Gießen, Gießen, Germany
2 Frauenklinik der medizinischen Universität Graz, Graz, Austria
3 LKH Villach, Villach, Austria
4 MMF Research GmbH, Münster, Germany
5 Institut für Epidemiologie, Sozialmedizin und Gesundheitssystemforschung, Medizinische Hochschule Hannover, Hannover, Germany
6 Johanniter GmbH; Evangelisches Krankenhaus Bethesda, Mönchengladbach, Germany
7 Drammen Hospital, Drammen, Norway
8 Städtisches Klinikum Karlsruhe, Karlsruhe, Germany
9 Universitätsfrauenklinik Tübingen, Tübingen, Germany
10 Stiftung Endometriose-Forschung, Westerstede, Germany
11 Praxisklinik am Rosengarten, Mannheim, Germany
12 Klinik für Frauenheilkunde, Geburtshilfe und Reproduktionsmedizin, Universitätskliniken des Saarlandes, Homburg/Saar, Germany
13 Frauenärzte am Staden, Saarbrücken, Germany
14 Klinik für Frauenheilkunde und Fortpflanzungsmedizin Universitätsklinikum Jena, Jena, Germany
15 Endometriosezentrum Keckstein, Villach, Austria
16 Klinik für Frauenheilkunde und Geburtshilfe, Universitätsklinikum Ulm, Ulm, Germany
17 Rehaklinik für Gynäkologie, Eisenmoorbad AG, Bad Schmiedeberg, Germany

Key words

endometriosis, quality assurance, reality of current care, healthcare research

Schlüsselwörter

Endometriose, Qualitätssicherung, Versorgungsrealität, Versorgungsforschung

| | |
|---|---|
| received | 13.1.2023 |
| accepted after revision | 19.3.2023 |
| published online | 23.5.2023 |

Bibliography

Geburtsh Frauenheilk 2023; 83: 835–842
DOI 10.1055/a-2061-6845
ISSN 0016-5751



Georg Thieme Verlag KG, Rüdigerstraße 14, 70469 Stuttgart, Germany

* These authors contributed equally to the publication.

** Members of the QS Endo Working Group who attended the Weissensee conferences of the SEF in 2016, 2017, and 2018: Dubravko Barisic, Alexander Boosz, Claus-Peter Cornelius, Iris Brandes, Klaus Bühler, Gerald Fischerlehner, Nannette Grübling, Elisabeth Janschek, Bernhard Krämer, Anna Kubus, Ivo Meinhold-Heerlein, Frank Oehmke, Peter Oppelt, Ralf Rothmund, Darius Salehin, Chi Mi Scheible, Miriam Schempershofe, Vanadin Seifert-Klauss, Omar Shebl, Kathrin Steinberger, Daniela Söffge, Sigrid Vingerhagen-Pethick, Peter Widschwendter, Pauline Wimberger, Monika Wölfler, Felix Zeppernick, Magdalena Zeppernick.

**Correspondence**
Prof. Ivo Meinhold-Heerlein, MD
Zentrum für Frauenheilkunde und Geburtshilfe
der Justus Liebig-Universität Gießen
Klinikstraße 33, 35392 Gießen, Germany
ivo.meinhold-heerlein@gyn.med.uni-giessen.de

Deutsche Version unter:
https://doi.org/10.1055/a-2061-6845
Supplementary material is available under
https://doi.org/10.1055/a-2061-6845

## ABSTRACT

**Introduction** Endometriosis significantly reduces patients' quality of life and is additionally a burden on healthcare and social security systems. There are currently no quality indicators for the treatment of endometriosis. The care of patients with endometriosis must be considered inadequate. QS ENDO aims to record the quality of care available in the DACH region and to introduce quality indicators for the diagnosis and treatment of endometriosis as part of providing quality assurance in endometriosis care. The first phase, QS ENDO Real, recorded the reality of current care using a questionnaire. The second phase, QS ENDO Pilot, investigated the treatment of 435 patients who underwent surgical treatment within a defined one month period in certified endometriosis centers.

**Material and Methods** An online tool was used to gather information about 9 points which covered both prior patient history and the process of clinical diagnosis. Surgery reports were reviewed to obtain information about the surgical approach, the investigated sites, findings of any histological examinations, the use of classification systems, and information about resection status.

**Results** 85.3% of patients were asked all 4 questions about their prior medical history. All 5 diagnostic steps were carried out in 34.5% of patients. The 3 areas needed to describe potential sites of disease were recorded in 67.1% of patients. Samples for histological examination were taken in 84.1% of patients. The endometriosis stage was classified in 94.7% of surgeries. A combination of the rASRM and the ENZIAN classifications, which is needed for complex cases, was used in 46.1% of patients. Complete resection was achieved in 81.6% of surgical procedures.

**Conclusion** For the first time, the quality of care in certified endometriosis centers has been recorded using QS ENDO Pilot. Despite the high certification standards, a substantial number of required indicators were omitted.

## ZUSAMMENFASSUNG

**Einleitung** Endometriose schränkt die Lebensqualität der Patientinnen bisweilen erheblich ein und belastet darüber hinaus die Gesundheits- und Sozialsysteme. Bisher fehlen Qualitätsindikatoren für die Behandlung. Die Versorgung von Patientinnen mit Endometriose wird als unzureichend angesehen. QS ENDO soll die Versorgungsqualität in der DACH-Region erfassen und im Sinne der Qualitätssicherung Qualitätsindikatoren für die Diagnostik und Therapie der Endometriose einführen. In der 1. Stufe QS ENDO Real wurde anhand eines Fragebogens die Versorgungsrealität erfasst. In der 2. Phase QS ENDO Pilot wurde die Behandlung von 435 Patientinnen, die innerhalb eines definierten 1-monatigen Zeitraums an den zertifizierten Endometriosezentren operiert wurden, untersucht.

**Material und Methoden** Mithilfe eines Online-Tools wurden 9 Punkte zur Anamnese und klinischen Untersuchung abgefragt. Anhand des OP-Berichts wurden u. a. der Zugangsweg, die Beschreibung des OP-Situs, eine etwaige histologische Sicherung und Anwendung einer Klassifikation sowie die Angabe des Resektionsstatus dokumentiert.

**Ergebnisse** Bei 85,3% der Patientinnen wurden alle 4 Anamnesefragen gestellt. Bei 34,5% wurden alle 5 Diagnostikschritte durchgeführt. Bei 67,1% wurden die 3 geforderten Areale des Situs beschrieben. Bei 84,1% erfolgte eine Probenentnahme zum histologischen Nachweis. Bei 94,7% der Operationen wurde das Stadium klassifiziert. Eine für komplexe Fälle notwendige Kombination der rASRM- und der ENZIAN-Klassifikation wurde bei 46,1% angewendet. Bei 81,6% der Operationen wurde eine Komplettresektion erzielt.

**Schlussfolgerung** Mit QS ENDO Pilot ist es erstmalig gelungen, die Versorgungsqualität in den zertifizierten Endometriosezentren zu erfassen. Trotz des hohen Zertifizierungsstandards werden die geforderten Indikatoren zu einem wesentlichen Anteil nicht berücksichtigt.

## Introduction

Endometriosis is a disease which develops during puberty and female sexual maturity; its prevalence is still very much underestimated [1]. The reported incidence in around 10–15% of all premenopausal women [2, 3] is almost certainly considerably higher because of the taboos surrounding the disease [4].

There are many indications that the term endometriosis is being used to subsume clinically, histologically, and molecularly very different entities [5]. According to the definition, endometrium-like tissue is found outside the uterine cavity in all forms of the disease. The risk of developing ovarian cancer is higher [6–8]. An association between deep infiltrating endometriosis and cervical cancer has been reported [9].

As symptoms are very diverse, misdiagnosis is common. The most important symptom is dysmenorrhea. Many patients additionally suffer from dysuria, several of them experience dyspareunia and dyschezia. If the disease remains untreated over a longer period of time, patients may experience non-menstrual pain. Sensitivity disorders and reduced motor function of the legs may occur if the nerves are affected. Many patients require chronic analgesics. Disorders of bladder and bowel function, dyspareunia and difficulties in conceiving significantly impair patients' quality of life [10, 11]. The last resort for treatment-resistant pain or func-

tional disorders of the bladder or bowels is lumbosacral neuromodulation [12]. Even patients who receive optimal primary treatment require continuous comprehensive care, as the disease affects key aspects in the life of young women. Relationship breakups and terminations of employment are not uncommon [10]. Endometriosis is also a significant social burden on healthcare and social security systems [13].

The definitive diagnosis can only be obtained following a histological examination. However, according to the revised guideline of the ESHRE, the use of laparoscopy to obtain the diagnosis is only necessary in cases where imaging is negative, as dynamic transvaginal ultrasound and/or magnetic resonance imaging are reliable methods to diagnose endometriosis [14] and laparoscopic surgery should be reserved for treatment. In future, the disease could be confirmed by non-invasive analysis of blood biomarkers or even salivary microRNAs which would avoid the need to perform diagnostic surgery [15, 16].

One of the major problems is the long latency period of 7–10 years between the first occurrence of symptoms and diagnosis. This dramatic delay shows that the prevalence of disease is not just underestimated by medical laypeople but also by general practitioners, pediatricians, and gynecologists [17 – 19].

In addition to the lack of or delayed diagnosis, there is the question whether, despite the widespread availability of endometriosis centers, the treatment of endometriosis generally follows standard best practice [20].

The positive results following an analysis of healthcare structures and quality assurance indicators for ovarian cancer (QS OVAR) by the Organ Commission Ovary of the Gynecological Oncology Working Group (*Arbeitsgemeinschaft Gynäkologische Onkologie*, AGO) prompted the idea that a similar analysis could be carried out for endometriosis [21, 22]. The analysis of ovarian cancer showed that structured training of the healthcare professionals providing treatment increased the probability that patients would receive the recommended therapy [23].

Quality indicators for the treatment of endometriosis have not been implemented to date. Accordingly, it is currently not possible to investigate the quality of currently available care [24]. QS ENDO aims to identify indicators which can be used to measure the quality of care.

The first phase of QS ENDO Real documented the reality of endometriosis care currently available in the DACH region (i.e., Germany [D], Austria [A], Switzerland [CH]), based on a questionnaire which was completed by the medical management of the participating care institutions [20, 25].

In the recently completed second phase of QS ENDO Pilot, the actual therapy provided in level II and III endometriosis centers over a one-month period was examined, using defined patient records.

The aim of the study was to review the implementation of existing standards required for certification as well as the compliance with guideline-adherent therapy. QS ENDO Pilot additionally aimed to review the quality indicators developed by a panel of experts and evaluate the feasibility of an online-based inquiry about the indicators. The circumscribed and clearly defined cohort of certified endometriosis centers was considered a suitable object of investigation. QS ENDO Pilot will serve as a preliminary study for the third phase named QS ENDO Study. The latter will be investigating the care of endometriosis patients in **all** institutions of the DACH region.

## Material and Methods

The obligation of clinical and clinical-scientific endometriosis centers to participate in QS ENDO Pilot was mandated by the board of the Endometriosis Research Foundation (*Stiftung Endometrioseforschung*, SEF).

### Patient cohort, period of observation

In October 2017, the medical management of certified endometriosis centers in Germany, Austria, and Switzerland (n = 44) were contacted. Every center was instructed to record the clinical data of 10 female patients in their center based on the respective patient files. Centers were requested to document the last 10 patients who underwent surgery in the respective center in October 2016. An online, specially developed documentation system was used to record the data, and the data of 439 patients was recorded. Four cases where no endometriosis could be confirmed were excluded from the study. One center had only 9 documented cases. Ultimately, the data of 435 patients were evaluated (n = 435).

The catalog of questions was developed by a panel of experts from the Endometriosis Research Foundation (SEF) and were approved by the Foundation's advisory board. The criteria were determined based on the then valid S2k guideline "Endometriosis" [26] or on proposals by the panel for quality indicators.

Information about age, height, weight, previous surgical procedures and previously undergone assisted reproduction procedures were collected for every patient. Data entry was anonymized for all cases. It is not possible to refer back to the respective center.

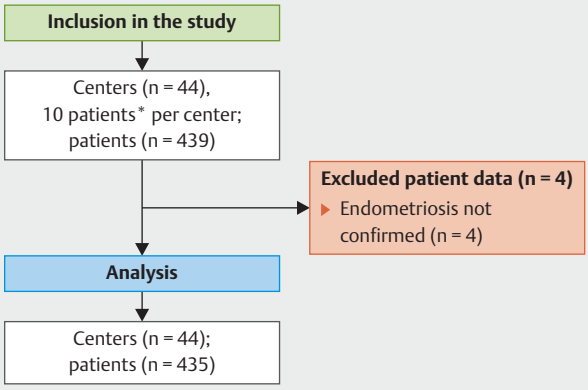
### Prior medical history and diagnostic steps, surgery report

The questions about patients' prior history focused on the indicators "dysmenorrhea", "urination problems", "defecation problems" and "dyspareunia". The indicators for clinical examination included "speculum examination," "bimanual palpation," "transvaginal ultrasound," "rectal examination," and "renal ultrasound." The surgery report was used to identify the approach taken, the surgical steps, the documentation of the site, any histological samples taken, the use of a classification system, and any complications [27, 28].

Reasons had to be given if resection was not complete. Recommendations for further treatment had to be stated.

### Statistical analysis

Data analysis was carried out after all data had been entered in accordance with the intention-to-treat principle. Statistical data analysis was performed using SPSS 21 (IBM Corp., released 2016). As this was an explorative study, evaluation of all variables was primarily descriptive. Further details on materials and methods are available in the eSupplement.




▶ **Fig. 1** Consort Chart. * Documented cases per center: one center only documented nine cases.

# Results

## Characteristics of participating centers

A total of 44 endometriosis centers participated in the study and they provided data for a total of 435 surgical cases (▶ **Fig. 1**). Three of the centers were in Austria, three were in Switzerland, and 38 centers were in Germany. Ten of the institutions were hospitals offering basic and standard medical care *(Grund- und Regelversorgung)*, one facility (25.6%) was a hospital with affiliated physicians *(Belegarztklinik)*, and 33 institutions (76.7%) were hospitals providing specialist or maximum care *(Schwerpunkt- oder Maximalversorgung)*. 93.2% of the centers performed more than 100 surgical interventions per year. As all institutions participating in the study were certified endometriosis centers, the results are presented as representing the totality of all centers.

Of the participating centers, 100% cooperated with a surgical department, 90.9% with a pathology department, 97.7% with a radiology and 90.9% with a urological department.

Every center held a regular dedicated endometriosis clinic.

## Basic patient data

Basic patient data are shown in ▶ **Table 1**. Median patient age at surgery was 34 (16–57) years. 35.9% of patients reported at least one previous pregnancy, and 27.6% reported giving birth at least once. 42.5% of women who had given birth (n = 120) were delivered by caesarean section. 8.0% of all patients reported a previous assisted reproduction intervention and 48.7% had had at least one previous abdominal surgery. The most common reason for presenting to the clinic was dysmenorrhea (60.5%), followed by referral by a specialist (57.7%), lower abdominal pain (57.5%), the wish to have children (34.3%), personal initiative of the patient (6.2%), the wish to obtain a second opinion (3.7%), and emergency presentation (2.3%).

## Previous history and diagnosis

Dysmenorrhea was the cardinal symptom of endometriosis according to the statements of 96.1% of patients. In 44.7% of these patients, dysmenorrhea was quantified using an analog scale. Median pain intensity was 7 (range: 1–10) with a mean of 6.3 on the numerical analog scale. 93.8% of patients were asked about pain during urination. 94% of patients were asked about dyschezia, and 87.8% were asked about dyspareunia. A speculum examination was carried out in 99.8% and transvaginal ultrasound was performed in 99.5% of patients. Bimanual pelvic examination was carried out in 98.4%, rectal examination in 54.3%, and renal ultrasound was recorded for 55.4% of patients (▶ **Fig. 2**).

85.3% of patients were asked all four questions pertaining to their medical history, 7.6% were asked three questions and the remaining 7.1% were asked fewer than three questions. All 5 diagnostic steps were carried out in 34.5% of patients, 4 steps were carried out in 39.3%, and only 3 steps were performed in 25.3% of cases. If the rectal examination was not included, the picture was as follows: 4 steps were carried out in 54.3% of patients, and 3 steps were carried out in 44.6%.

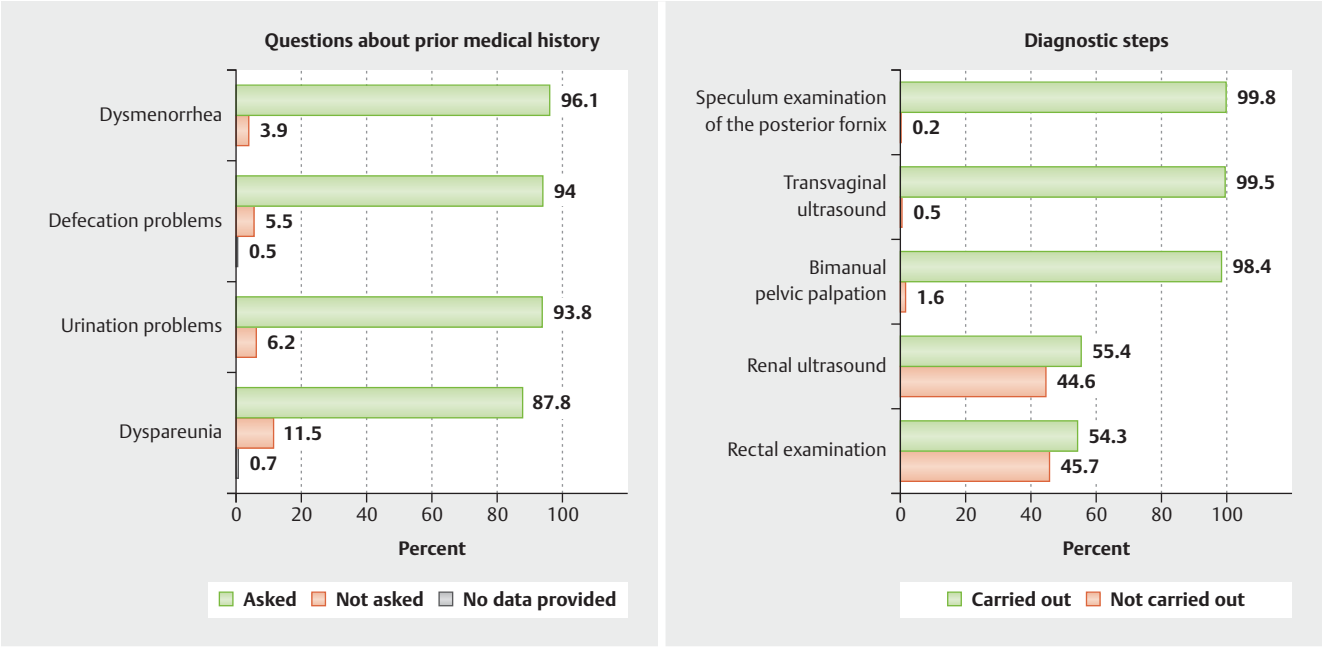
When the questions about patients' medical history and the diagnostic steps performed were summarized into nine quality indicators, the overall picture was as follows: all nine quality indicators were recorded for 32.4% of patients, eight were recorded for 36.8%, seven for 18.4%, six for 6.7%, and five or less were recorded for the remaining 5.8% of cases. If the rectal examination was not included in the analysis, the picture was as follows: all eight indicators were recorded for 48.7% of patients, seven indicators for 38.2%, six indicators for 6.9% and five or less indicators were reported for the remaining 6.2% of patients.

## Surgery

The percentage of laparoscopic surgical interventions was 96.1% and the percentage of open surgeries was 1.8%. Conversion to laparotomy was required in 1.4% of cases. "Another approach" was reported for 0.7% of cases. The percentage of primary surgeries was 74.0% and 26.0% of procedures were operations for recurrence, although the number of prior surgeries ranged between

▶ **Table 1** Basic patient data (age, weight, height, body mass index [BMI]).

| | Mean | Median | Minimum | Maximum | Number (n) |
|---|---|---|---|---|---|
| Age in years | 34.7 | 34 | 16 | 57 | 435 |
| Weight in kg | 68.5 | 66 | 42 | 130 | 424 |
| Height in cm | 167.4 | 168 | 150 | 185 | 424 |
| BMI in kg/m² | 24.5 | 23.2 | 15.6 | 46.4 | 424 |




▶ **Fig. 2** QS ENDO Pilot – Taking patients' medical history and diagnostic steps based on patient files (n = 435).

1 and 7, and 14.2% of patients had had three or more prior operations. A tissue sample for histological verification was obtained in 84.1% of all surgeries, and endometriosis was confirmed by histopathology in 97.3% of cases.

### Documentation of the site

The investigated site was documented in 95.4% of patients. The following areas were specifically reviewed: minor pelvis, subphrenic peritoneal tissue, ileocecal pole. Complete intraoperative documentation covering all three areas was done for 67.1% of patients. Fewer than three areas were described in the surgery reports of 26.9% of cases and no information about the site was provided in 6.0% of cases.

### Classification

Endometriosis was classified for 94.7% of patients. The revised classification of the American Society of Reproductive Medicine (rASRM) was primarily used to classify peritoneal and ovarian endometriosis and the ENZIAN classification to classify deep infiltrating endometriosis. As deep infiltrating endometriosis is unlikely to occur in isolation, simultaneous use of the rASRM and ENZIAN classifications is usually necessary for a comprehensive classification. This was done in 46.1% of cases.

### Postoperative absence of endometriosis

Macroscopic complete resection at the end of the operation was reported for 81.6% of patients. The reasons for incomplete resection of endometriosis are shown in ▶ **Fig. 3**.

### Complications

Complications were only reported for a few patients treated in institutions of maximum care. The incidence of perioperative complications in these institutions was low, amounting to just 2.8% (12/328).

### Further treatment recommended

A recommendation for further treatment was included in the surgical report or doctor's letter for 91.3% of patients.

## Comparison with QS ENDO Real: medical history and diagnosis

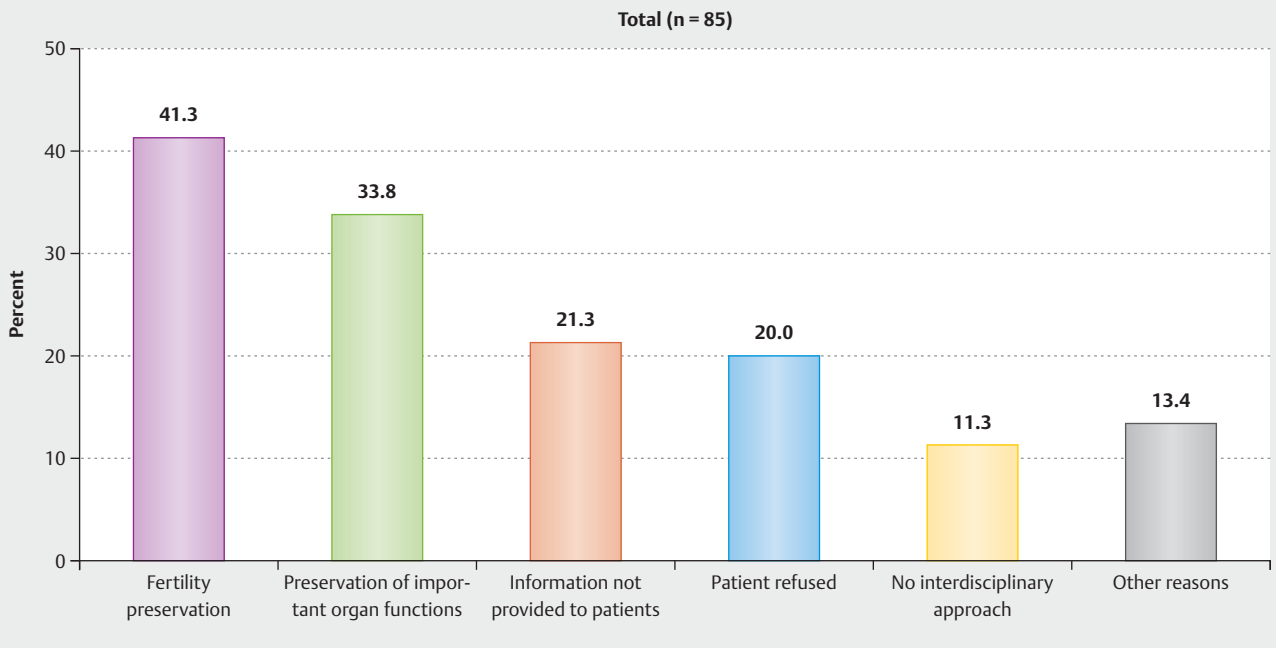
28 centers participated in both QS ENDO Real and QS ENDO Pilot. The data of 269 patients from these centers was documented in QS ENDO Pilot. In the institutions where the medical management described all four questions regarding patients' medical history as "very important", 86.8% of the patients documented in QS ENDO Pilot were asked all four questions.

In the institutions where the medical management considered all five diagnostic steps to be "absolutely necessary," the five diagnostic steps were carried out in 45.0% of cases. If the parameter "rectal examination" was not included, the percentage increased to 73.4%.

# Discussion

QS ENDO aims to record the reality of care provided to patients with endometriosis in German-speaking countries in Europe, compile verifiable quality indicators, and highlight relevant deficiencies. It is indisputable that the time between occurrence of the first symptom and the ultimate diagnosis of endometriosis needs to be reduced. Moreover, all patients should be treated in accordance with the guidelines.

QS ENDO consists of four phases: QS ENDO Real, QS ENDO Pilot, QS ENDO Study and QS ENDO Follow-up. QS ENDO Real re-




▶ **Fig. 3** QS ENDO PILOT – reasons for incomplete resection. Data in percent.

corded the reality of endometriosis care based on the results of a questionnaire which was completed by the medical management of endometriosis centers [25]. In the three subsequent phases, the quality of care will be investigated based on the treatment of individual patients.

The second phase of the study described in this article (QS ENDO Pilot) examined the treatment provided to 10 patients from every participating level II or III endometriosis center over a period of one month. In phase 3 (QS ENDO Study), this review of treatment will be expanded to cover all treating hospitals in the DACH region. The fourth phase (QS ENDO Follow-up) aims to generate data for long-term prognosis of patients including the pregnancy rate [20, 25].

One finding of QS ENDO Real was that only around one third of all endometriosis patients are treated in certified centers. This implies that quality control measures must not be limited to certification measures, as these will not reach the majority of endometriosis patients. In addition to gynecologists, it is very important to also include pediatricians, specialists for internal medicine, surgeons, urologists, and general practitioners of medicine and enable them to recognize the disease in all its manifestations at an early stage and provide appropriate treatment [25].

QS ENDO Pilot aimed to evaluate whether quality indicators based on different national guidelines selected by the panel of experts from the Endometriosis Research Foundation were actually being applied in certified endometriosis centers [29].

A central part of the analysis was to find out whether four key questions about patients' medical history were actually being asked in practice. More than 96.1% of patients were asked about the cardinal symptom "dysmenorrhea," but the extent of dysmenorrhea was only quantified using a numerical analog scale (NAS) in 44.7% of cases. Efforts to ensure comparability between centers mean that it will be necessary to demand the introduction of pain scores [30].

Median pain intensity on the numerical analog scale was 7. Half of the patients had had at least one prior operation, 14.2% had even had three or more previous surgeries. This shows that endometriosis centers are often dealing with complex cases and that many of their patients already have a long clinical history of illness and high levels of pain.

Another key question was whether all five essential diagnostic steps were carried out. Bimanual pelvic palpation, speculum examination, and transvaginal ultrasound were carried out in almost 100% of cases. For the speculum examination, inspection of the posterior vaginal fornix was not explicitly mandated; the importance of carrying out this inspection should be made clear in future. However, a rectal examination was only carried out in 56% of patients and results of a renal ultrasound were only documented in 57.8% of cases. At the time of carrying out this study, neither of these two examinations had been incorporated in the currently valid S2k guideline. But in some instances, deep infiltrating endometriosis can only be detected with a rectal examination. This issue continues to be controversially discussed and it was not included in the current guideline as an obligatory examination [31]. Several authors have reported that for rectovaginal endometriosis, clinical examination has a high sensitivity of 95.2% [32, 33]. Ureteral endometriosis is sometimes clinically inapparent. But in around 25–50% of cases, hydronephrosis with renal failure is a very real threat. For this reason, according to current guidelines, bilateral renal ultrasound should be carried out if there is a suspicion of deep infiltrating endometriosis or ovarian endometriosis [31, 34–36].

To get an approximate idea of the percentage of patients who underwent what the panel of experts considered to be optimal questioning about their medical history followed by an appropriate diagnostic investigation, the study investigated how many patients were evaluated using all nine key parameters (four questions and five diagnostic steps). It was found that this was only the case for 32.44% of patients. If the controversial rectal examination was not included, the percentage increased to 48.7%. This is reason enough to take a closer look at basic key aspects of the certification process and demand that they become an essential part of the guidelines!

A total of 28 centers participated both in QS ENDO Real and in QS ENDO Pilot. The recorded data of 269 patients from these centers showed that the four questions about patients' previous medical history were only asked in 86.8% of cases and all diagnostic steps were only recorded for 45.0% of cases – even if the center management viewed these parameters as "absolutely necessary". If the actual percentages reported are so low for certified centers where the medical management considers the quality of care as evinced by taking patients' medical history and carrying out appropriate diagnostic steps to be very important, this suggests that the quality of care provided to endometriosis patients overall is inadequate.

When the examination of potential sites of disease were documented, the "subphrenic space and "terminal ileum" were not included in around one third of cases. It is important not to overlook these areas as the diaphragm is affected in 1–1.5% and the appendix in 0.5% of all cases with endometriosis [37, 38].

The revised classification of the American Society of Reproductive Medicine (rASRM) was primarily used to classify peritoneal and ovarian endometriosis and the ENZIAN classification to classify deep infiltrating endometriosis. As deep infiltrating endometriosis usually does not appear in isolation, simultaneous use of the rASRM and ENZIAN classifications is necessary to obtain a comprehensive classification. This was done in 46.1% of cases. In future, the expanded #ENZIAN classification will represent all clinically relevant lesions including peritoneal, ovarian, and deep infiltrating lesions in a single classification. This should lead to a higher rate of application [27, 28, 39].

Complete resection at the end of surgery was not achieved in 18.4% of patients. While in some cases the reasons for this are easily comprehensible (e.g., the preservation of fertility), it is not acceptable that appropriate surgical information was missing in 22% of cases and an interdisciplinary approach was not used in 11% of cases.

In future, it will be essential in the context of the QS ENDO Study to not just evaluate the quality of care provided by certified endometriosis centers but to evaluate the quality of care provided by all facilities in the DACH region which treat endometriosis patients. As the majority of all endometriosis patients are treated outside certified centers, these data will be the starting point to highlight potential deficiencies in treatment and introduce measures to improve the quality of care. In addition to a more severe audit which will not only review the quality of structures and processes but also the quality of care, measures must include further training and education of all physicians treating young women affected by endometriosis. The taboo surrounding endometriosis must be overcome and the current period of an entire decade between the first symptom and the diagnosis must be dramatically reduced. For a disease which affects so many young women, it is about time [25, 40]!

## Conclusion

Deficits in guideline-adherent care are present even in certified endometriosis centers. The upcoming third phase, QS ENDO Study, will be evaluating the quality of care provided to endometriosis patients in the DACH region. As the majority of patients receive their treatment outside certified centers, the data obtained from this study will provide an important basis for measures to improve care.


## Acknowledgements

We would like to thank Prof. J. Pfisterer and Prof. A. du Bois for their support during the structural and scientific development of QS ENDO. Our thanks also go to the team at MMF for carrying out the survey and evaluating the responses. Many thanks also go to the participating centers for their strong commitment and for providing detailed online documentation of their patients based on their patient files at such short notice.

We would like to thank the companies Karl Storz, Gedeon Richter, Jenapharm, Bayer and Takeda as well as Roche Diagnostics for unrestricted grants to the Endometriosis Research Foundation. The project was carried out independently and has no commercial goals.


## Conflict of Interest

The authors declare that they have no conflict of interest.

## References


[1] Sampson JA. Peritoneal endometriosis due to the menstrual dissemination of endometrial tissue into the peritoneal cavity. Am J Obstet Gynecol 1927; 14: 422–469. doi:10.1016/S0002-9378(15)30003-X

[2] Burney RO, Giudice LC. Pathogenesis and pathophysiology of endometriosis. Fertil Steril 2012; 98: 511–519. doi:10.1016/j.fertnstert.2012.06.029

[3] Mowers EL, Lim CS, Skinner B et al. Prevalence of endometriosis during abdominal or laparoscopic hysterectomy for chronic pelvic pain. Obstet Gynecol 2016; 127: 1045–1053

[4] Koninckx PR, Ussia A, Adamyan L et al. The epidemiology of endometriosis is poorly known as the pathophysiology and diagnosis are unclear. Best Pract Res Clin Obstet Gynaecol 2021; 71: 14–26. doi:10.1016/j.bpobgyn.2020.08.005

[5] Anglesio MS, Papadopoulos N, Ayhan A et al. Cancer-Associated Mutations in Endometriosis without Cancer. N Engl J Med 2017; 376: 1835–1848. doi:10.1056/NEJMoa1614814

[6] Pearce CL, Templeman C, Rossing MA et al. Association between endometriosis and risk of histological subtypes of ovarian cancer: A pooled analysis of case-control studies. Lancet Oncol 2012; 13: 385–394. doi:10.1016/S1470-2045(11)70404-1

[7] Grandi G, Toss A, Cortesi L et al. The Association between Endometriomas and Ovarian Cancer: Preventive Effect of Inhibiting Ovulation and Menstruation during Reproductive Life. Biomed Res Int 2015. doi:10.1155/2015/751571

[8] Krawczyk N, Banys-Paluchowski M, Schmidt D et al. Endometriosis-associated Malignancy. Geburtshilfe Frauenheilkd 2016; 76: 176–181. doi:10.1055/s-0035-1558239

[9] Saavalainen L, Lassus H, But A et al. Risk of Gynecologic Cancer According to the Type of Endometriosis. Obstet Gynecol 2018; 131: 1095–1102. doi:10.1097/AOG.0000000000002624

[10] De Graaff AA, D'Hooghe TM, Dunselman GAJ et al. The significant effect of endometriosis on physical, mental and social wellbeing: Results from an international cross-sectional survey. Hum Reprod 2013; 28: 2677–2685. doi:10.1093/humrep/det284

[11] Facchin F, Barbara G, Saita E et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. J Psychosom Obstet Gynaecol 2015; 36: 135–141. doi:10.3109/0167482X.2015.1074173

[12] Kolodziej M, Uhl E, Schwarm F et al. Interdisciplinary Laparoscopic Implantation of Neuromodulation Leads to the Sacral Plexus for Therapy of Chronic Pelvic Pain and Neurogenic Bladder Dysfunctions. Neuromodulation 2020; 23: 1151–1157. doi:10.1111/ner.13157

[13] Simoens S, Dunselman G, Dirksen C et al. The burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012; 27: 1292–1299. doi:10.1093/humrep/des073

[14] Becker CM, Bokor A, Heikinheimo O et al.; ESHRE Endometriosis Guideline Group. ESHRE guideline: endometriosis. Hum Reprod Open 2022; 2022: hoac009. doi:10.1093/hropen/hoac009

[15] Nisenblat V, Bossuyt PM, Shaikh R et al. Blood biomarkers for the non-invasive diagnosis of endometriosis. Cochrane Database Syst Rev 2016; (5): CD012179. doi:10.1002/14651858.CD012179

[16] Bendifallah S, Suisse S, Puchar A et al. Salivary MicroRNA Signature for Diagnosis of Endometriosis. Accessed May 01, 2023 at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8836532/pdf/jcm-11-00612.pdf

[17] Nnoaham KE, Hummelshoj L, Webster P et al. Impact of endometriosis on quality of life and work productivity: A multicenter study across ten countries. Fertil Steril 2011; 96: 366–373.e8. doi:10.1016/j.fertnstert.2011.05.090

[18] Hudelist G, Fritzer N, Thomas A et al. Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. Hum Reprod 2012; 27: 3412–3416. doi:10.1093/humrep/des316

[19] Staal AHJ, Van Der Zanden M, Nap AW. Diagnostic Delay of Endometriosis in the Netherlands. Gynecol Obstet Invest 2016; 81: 321–324. doi:10.1159/000441911

[20] Zalewski M, Zeppernick F, Wölfler MM et al. Pattern of Endometriosis Care in German-speaking Countries: the QS ENDO Project. J Reproduktionsmed Endokrinol 2017; 14: 311–312

[21] du Bois A, Rochon J, Lamparter C et al. [The Quality Assurance Program of the AGO Organkommission OVAR (QS-OVAR): Pattern of Care and Reality in Germany 2001]. Zentralbl Gynakol 2005; 127: 9–17. doi:10.1055/s-2005-836289

[22] Harter P, Pfisterer J, Hilpert F et al. Therapiequalität des fortgeschrittenen Ovarialkarzinoms in Deutschland. Frauenarzt 2020; 61: 182–188

[23] Munoz KA, Harlan LC, Trimble EL. Patterns of care for women with ovarian cancer in the United States. J Clin Oncol 1997; 15: 3408–3415

[24] Schweppe KW, Ebert AD, Kiesel L. Endometriosezentren und Qualitätsmanagement. Gynäkologe 2010; 43: 233–240. doi:10.1007/s00129-009-2484-x

[25] Zeppernick F, Zeppernick M, Janschek E et al. QS ENDO Real – A Study by the German Endometriosis Research Foundation (SEF) on the Reality of Care for Patients with Endometriosis in Germany, Austria and Switzerland. Geburtshilfe Frauenheilkd 2020; 80: 179–189. doi:10.1055/a-1068-9260

[26] Ulrich U, Buchweitz O, Greb R et al.; German and Austrian Societies for Obstetrics and Gynecology. National German Guideline (S2k): Guideline for the Diagnosis and Treatment of Endometriosis: Long Version – AWMF Registry No. 015–045. Geburtshilfe Frauenheilkd 2014; 74: 1104–1118. doi:10.1055/s-0034-1383187

[27] Revised American Society for Reproductive Medicine classification of endometriosis: 1996. Fertil Steril 1997; 67: 817–821

[28] Tuttlies F, Keckstein J, Ulrich U et al. [ENZIAN-score, a classification of deep infiltrating endometriosis]. Zentralbl Gynakol 2005; 127: 275–281. doi:10.1055/s-2005-836904

[29] Ferron G, Martinez A, Gladieff L et al. Adherence to guidelines in gynecologic cancer surgery. Int J Gynecol Cancer 2014; 24: 1675–1678. doi:10.1097/IGC.0000000000000284

[30] Bourdel N, Alves J, Pickering G et al. Systematic review of endometriosis pain assessment: how to choose a scale? Hum Reprod Update 2015; 21: 136–152. doi:10.1093/humupd/dmu046

[31] Burghaus S, Schäfer SD, Beckmann MW et al. Diagnosis and Treatment of Endometriosis. Guideline of the DGGG, SGGG and OEGGG (S2k Level, AWMF Registry Number 015/045, August 2020) Geburtshilfe Frauenheilkd 2021; 81: 422–446. doi:10.1055/a-1380-3693

[32] Chen YH, Wang DB, Guo CS. Accuracy of Physical Examination, Transvaginal Sonography, Magnetic Resonance Imaging, and Rectal Endoscopic Sonography for Preoperative Evaluation of Rectovaginal Endometriosis. Ultrasound Q 2019; 35: 54–60. doi:10.1097/RUQ.0000000000000428

[33] Mangler M, Medrano N, Bartley J et al. Value of diagnostic procedures in rectovaginal endometriosis. Aust N Z J Obstet Gynaecol 2013; 53: 389–394. doi:10.1111/ajo.12108

[34] Palla VV, Karaolanis G, Katafigiotis I et al. Ureteral endometriosis: A systematic literature review. Indian J Urol 2017; 33: 276–282. doi:10.4103/iju.IJU_84_17

[35] Langebrekke A, Qvigstad E. Ureteral endometriosis and loss of renal function: Mechanisms and interpretations. Acta Obstet Gynecol Scand 2011; 90: 1164–1166

[36] Soriano D, Schonman R, Nadu A et al. Multidisciplinary Team Approach to Management of Severe Endometriosis Affecting the Ureter: Long-term Outcome Data and Treatment Algorithm. J Minim Invasive Gynecol 2011; 18: 483–488. doi:10.1016/j.jmig.2011.04.011

[37] Kaveh M, Tahermanesh K, Kashi AM et al. Endometriosis of Diaphragm: A Case Report. Int J Fertil Steril 2018; 12: 263–266. doi:10.22074/ijfs.2018.5379

[38] Gustofson RL, Kim N, Liu S et al. Endometriosis and the appendix: a case series and comprehensive review of the literature. Fertil Steril 2006; 86: 298–303. doi:10.1016/j.fertnstert.2005.12.076

[39] Keckstein J, Saridogan E, Ulrich UA et al. The #Enzian classification: A comprehensive non-invasive and surgical description system for endometriosis. Acta Obstet Gynecol Scand 2021; 100: 1165–1175

[40] Chapron C, Marcellin L, Borghese B et al. Rethinking mechanisms, diagnosis and management of endometriosis. Nat Rev Endocrinol 2019; 15: 666–682. doi:10.1038/s41574-019-0245-z