

Endometriosis Care in Vienna



A Synopsis of International Guideline Recommendations and Assessment of Healthcare Reality in Vienna

Final report

AIHTA Project Report No.: 187 | ISSN: 1993-0488 | ISSN-online: 1993-0496

Vienna, October 2026

Project Team

Project leader: Lena Grabenhofer, BA, MSc
Authors: Lena Grabenhofer, BA, MSc
Dr.med Doris Giess, MPH
Dr.med. Eleen Rothschedl

Project Support:

Hand search: Lena Grabenhofer BA, MSc.
Dr.med Doris Giess, MPH
Internal Review:: Christoph Strohmaier, MSc
Ingrid Zechmeister-Koss, Dr. rer. soc. oec., MA
External Review: Prof. Dr. med. Ludwig Kiesel
Assoz. Prof. PD OÄ Dr. Beata Seeber
Univ.Prof. Dr. René Wenzl

Correspondence: LG; lena.grabenhofer@aihta.at

Cover photo: @ AI-generated – [gemini.google.com](https://www.gemini.google.com)

Acknowledgements: During the preparation of this work, the authors used Claude.ai, DeepL.com and ChatGPT.com to enhance the writing process. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

This report should be referenced as follows:

Grabenhofer L., Giess D., Rothschedl E. Endometriosis Care in Vienna: A Synopsis of International Guideline Recommendations and Assessment of Healthcare Reality in Vienna. AIHTA Project Report No.: 187. Vienna: HTA Austria – Austrian Institute for Health Technology Assessment GmbH, 2026. Available from: <https://eprints.aihta.at/1627>.

Conflict of interest

All authors and the reviewers involved in the production of this report have declared they have no conflicts of interest in relation to the technology assessed according to the Uniform Requirements of Manuscripts Statement of Medical Journal Editors (www.icmje.org).

Disclaimer

The external reviewers did not co-author the scientific report and do not necessarily all agree with its content. Only the AIHTA is responsible for errors or omissions that could persist. The final version and the policy recommendations are under the full responsibility of the AIHTA.

IMPRINT**Publisher:**

HTA Austria – Austrian Institute for Health Technology Assessment GmbH
Josefstädter Straße 39 | 1080 Wien – Österreich
<https://www.aihta.at/>

Responsible for content::

Dr. rer. soc. oec. Ingrid Zechmeister-Koss, MA, managing director

AIHTA Project Reports do not appear on a regular basis and serve to publicize the research results of the Austrian Institute for Health Technology Assessment.

AIHTA Project Reports are available to the public at the institute's repository.
<http://eprints.aihta.at>

AIHTA Project Report No.: 187

ISSN 1993-0488

ISSN online 1993-0496

© 2026 AIHTA – All rights reserved

Content

Zusammenfassung	8
Summary	11
1 Background	14
1.1 Endometriosis	14
1.1.1 Definition and Pathophysiology	14
1.1.2 Epidemiology	14
1.1.3 Classification and Subtypes	15
1.1.4 Clinical Presentation	16
1.1.5 Diagnosis and Treatment	17
1.1.6 Impact and Disease Burden	18
1.1.7 Endometriosis in Austria	18
2 Research Question and Project Aim	20
3 Methods	21
3.1 General Overview	21
3.2 PICo and Literature Identification	21
3.3 Quality Assessment of the Guidelines	22
3.4 Data Extraction and Synthesis of Guidelines and Care Models	23
3.5 Empirical Studies	24
3.6 Assessment of Concordance with Guideline Recommendations	25
3.7 Quality Assurance	26
4 Results: Guidelines	27
4.1 Guideline Synopsis	27
4.1.1 Included Guidelines	27
4.1.2 Appraisal and Guideline Characteristics	27
4.2 Guideline Recommendations	30
4.2.1 Diagnostic Workup	31
4.2.2 Treatment of Endometriosis-Associated Pain	34
4.2.3 Treatment of Endometriosis-Associated Infertility	40
4.2.4 Recurrence of Endometriosis	42
4.2.5 Management of Asymptomatic Endometriosis	43
4.2.6 Follow-up Care and Rehabilitation	44
4.2.7 Endometriosis in Adolescents	44
4.3 Organisation and Delivery of Endometriosis Care	47
5 Results: Empirical Studies	50
5.1 Patient Survey	50
5.2 Healthcare Provider Survey	58
6 Results: Endometriosis Care: Guidelines Versus Clinical Practice in Vienna	67
7 Discussion	75
7.1 Summary of Findings	75
7.2 Critical Reflection	77
7.3 Limitations	81
8 Conclusio and Action Points	84
9 Literatur	86

Appendix.....	89
A-I Strength of Recommendation.....	89
A-II Patient Survey Graphs	93
A-III Healthcare Provider Survey Graphs	96
A-IV Surveys	100
A-V Positive Ethics Application	111

List of figures

Figure 1-1: Symptoms and Comorbidities of Endometriosis	16
Figure 4-1: Quality appraisal	28
Figure 4-2: Core Guideline-based approach to suspect endometriosis.....	46
Figure 5-1: Symptoms Prior to Diagnosis	52
Figure 5-2: Initial Investigations	53
Figure 5-3: First-line Treatments	53
Figure 5-4: Additional Treatments	53
Figure 5-5: Amount of direct cost	54
Figure 5-6: Information provided for patients.....	55
Figure 5-7: Impacts on Areas of Life	56
Figure 5-8: Rating of Healthcare Provision	57
Figure 5-9: Available Services	59
Figure 5-10: Diagnostic Procedures in suspected endometriosis.....	60
Figure 5-11: First line treatment in patients without a current wish to conceive.....	62
Figure 5-12: Indication for Surgical Treatment.....	62
Figure 5-13: Interdisciplinary Collaboration.....	63
Figure 5-14: Discrepancies between guidelines and practice	64
Figure 5-15: Discrepancies between guidelines and practice	65
Figure 5-16: Measures of Improvement.....	65
Figure A-1: Cultural Background.....	92
Figure A-2: Employment Status	92
Figure A-3: Highest Level of Education Figure A-4: Current Treatment in Vienna	92
Figure A-5: Symptoms Prior to Diagnosis	92
Figure A-6: Number of Doctors before Diagnosis.....	92
Figure A-7: Place of Diagnosis.....	93
Figure A-8: Initial Investigations	93
Figure A-9: Next Steps were Discussed.....	93
Figure A-10: Referral to Endometriosis Centre.....	93
Figure A-11: Internal Costs were Incurred	93
Figure A-12: Amount of Direct Costs.....	93
Figure A-13: Taking the Desire to have Children into Account	94
Figure A-14: First-line Treatment	94
Figure A-15: Additional Treatment.....	94
Figure A-16; Satisfaction with Current Treatment	94
Figure A-17: Provides Information in the Following Aspects.....	94
Figure A-18: Involved in Treatment Decisions	95

Figure A-19: Informed about Endometriosis.....	95
Figure A-20: Impact on Areas of Life.....	95
Figure A-21: Complaints not Taken Seriously	95
Figure A-22: Rating of Healthcare Provision	95
Figure A-23: Not Receive any Help.....	95
Figure A-24: Area of Practice.....	96
Figure A-25: Part of Endometriosis Centre	96
Figure A-26: Patient Volume	96
Figure A-27: Available Service.....	96
Figure A-28: Structured Pathway for Endometriosis.....	96
Figure A-29: Perceived Usefulness of Guidelines	96
Figure A-30: Basis of Structured Pathway	97
Figure A-31: Diagnostic Procedure	97
Figure A-32: Frequency of Transvaginal Ultrasounds.....	97
Figure A-33: Working Diagnosis without Laparoscopy	97
Figure A-34: Indication for Diagnostic Laparoscopy.....	97
Figure A-35: Indication for MRI Scan	97
Figure A-36: Use of Standardised Classification System.....	98
Figure A-37: First-line Treatment without a wish to conceive.....	98
Figure A-38: Indication for Surgical Treatment.....	98
Figure A-39: Sufficient Time for Treatment Decision	98
Figure A-40: Interdisciplinary Collaboration.....	98
Figure A-41: Sufficient Time to Decide on a Course of Treatment.....	98
Figure A-42: Management of Complex Cases	99
Figure A-43: Fertility-related Referral.....	99
Figure A-44: Preferred Strategy for those Wishing to have Children.....	99
Figure A-45: Management of Adolescent Patients	99
Figure A-46: Structural Barriers.....	99
Figure A-47: Discrepancies between Guidelines and Practice.....	99
Figure A-48: Improvement Measures.....	100

List of tables

Table 1-1: Subtypes of endometriosis adapted from International Working Group of AAGL, ESGE, ESHRE and WES	15
Table 3-1: PICO.....	21
Table 4-1: Characteristics of included guidelines	29
Table 4-2: Methodological characteristics of included guidelines	30
Table 4-3: Diagnostic work-up: Key recommendations strength and quality of evidence across guidelines.....	34
Table 4-4: Key recommendation strength and quality of evidence across guidelines	39
Table 4-5: Key recommendation strength and quality of evidence across guidelines	42
Table 4-6: Key recommendation strength and quality of evidence across guidelines	43

Table 4-7:	Management of Asymptomatic Endometriosis: Key recommendation strength and quality of evidence across guidelines.....	43
Table 4-8:	Follow-up Care and rehabilitation: Key recommendation strength and quality of evidence across guidelines.....	44
Table 4-9:	Adolescents: Key recommendation strength and quality of evidence across guidelines	45
Table 4-10:	Design of additional literature	47
Table 5-1:	Patient Sample.....	50
Table 5-2:	Diagnostic pathway and care setting	51
Table 5-3:	General Information	58
Table 5-4:	Diagnostic Practice	59
Table 5-5:	Diagnostic Work-Up	61
Table 5-6:	Fertility Management	64
Table 6-1:	Comparison of diagnostic procedures: guidelines vs. survey.....	67
Table 6-2:	Comparison of therapy: guidelines vs. survey.....	69
Table 6-3:	Comparison of treatment for infertility: guidelines vs. survey.....	71
Table 6-4:	Comparison of the treatment of adolescents: guidelines vs. survey	71
Table 6-5:	Comparison of Healthcare organisation and Patient experience: guidelines vs. survey	72
Table 6-6:	Comparison of shared decision-making and patient information: guidelines vs. survey.....	73
Table A-1:	Strength of recommendation ESHRE.....	89
Table A-2:	Certainty of recommendation RANZCOG	89
Table A-3:	Strength of recommendation RANZCOG	89
Table A-4:	Strength of recommendation NICE.....	90
Table A-5:	Certainty of recommendation RANZCOG	90
Table A-6:	Strength of recommendation AWMF	90
Table A-7:	Strength and certainty of recommendation HSE.....	91

List of abbreviations

AAGL	American Association of Gynaecological Laparoscopists	BMJ	British Medical Journal
AGREE II	Appraisal of Guidelines for Research & Evaluation II	BSGR	British Society of Gynaecological Endoscopy
AIHTA	Australian Institute for Health Technology Assessment	CA-125	Cancer Antigen 125
AKH	Allgemeines Krankenhaus (<i>engl. General Hospital</i>)	CAM.....	Complementary and Alternative medicine
AMH	Anti Müllerian Hormone	CBT	Cognitive Behavioural Therapy
ART.....	Assisted Reproductive Technology	CHC	Combined Hormonal Contraceptive
ASRM.....	American Society for Reproductive Medicine	COC	Combined Oral Contraceptive
AWMF	Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (<i>engl. Working Group of Scientific Medical Societies</i>)	CI.....	Confidence Interval
		COI.....	Conflict of Interest
		COREQ.....	Consolidated Criteria for Reporting Qualitative Research
		CT	Computed Tomography
		DACH	Deutschland, Österreich, Schweiz (<i>Germany, Austria, Switzerland</i>)

Dept	Department	LNIUS	Levonorgestrel-Releasing Intrauterine Systems
DGGG	Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (engl. <i>German Society for Gynaecology and Obstetrics</i>)	M	Mean Score
DIE.....	Deep Infiltrating Endometriosis	MDT	Multidisciplinary Care Team
EFI	Endometriosis Fertility Index	MRI	Magnetic Resonance Imaging
ELGA	Elektronische Gesundheitsakte (engl. <i>Electronic Health Record</i>)	NICE.....	National Institute for Health and Care Excellence
EMBASE.....	Excerpta Media Database	NIHR	National Institute of Health and Care Research
ESGE.....	European Society for Gynaecological Endoscopy	NSAIDs.....	Non-Steroidal Anti-Inflammatory Drugs
ESHRE.....	European Society of Human Reproduction and Embryology	NVOG	Dutch Society of Obstetrics and Gynecology
EU	European Union	OSF	Open Science Framework
FODMAP	Fermentable Oligo-, Di-, Monosaccharides and Polyols	ÖGK.....	Österreichische Gesundheitskasse
GA	General Anaesthesia	PET-CT	Positron Emission Tomography/ Computed Tomography
GDG	Guideline Development Group	PICo	Population, Interest/Phenomenon of Interest, Context
GIN	Guidelines International Network	QoL	Quality of life
GnRH.....	Gonadotropin-releasing hormone	RANZCOG...	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
GoR	Grade of Recommendation	rASRM	Revised American Society for Reproductive Medicine
GPP	Good Practice Point	RCT.....	Randomised Controlled Trial
GPS	Good Practice Statement	RQ	Research Question
GRADE.....	Grading of Recommendations Assessment, Development and Evaluation	SR.....	Systematic Review
HCP.....	Healthcare Provider	TA.....	Treatment Alternative
HSE.....	Health Service Executive	TAUS	Transabdominal Ultrasound
IU	International Unit	TENS	Transcutaneous Electrical Nerve Stimulation
IUD	Intrauterine Device	TVS/TVUS ...	Transvaginal Ultrasound
IVF	In Vitro Fertilisation	UK.....	United Kingdom
LoE.....	Level of Evidence	WES	World Endometriosis Society
LNG-IUS	Levonorgestrel-releasing Intrauterine System		

Note on terminology and inclusivity in this report

Endometriosis can affect individuals of diverse gender identities who have a uterus. This report therefore uses the terms “individuals” and “patients” rather than “women” to reflect this diversity, without denying that endometriosis is predominantly experienced by, and clinically understood as, a condition affecting the female reproductive system. The choice of terminology is intended to be inclusive, not to obscure the fact that women constitute the vast majority of those affected.

Zusammenfassung

Kernaussagen

- Endometriose ist eine chronische, gutartige Erkrankung, bei der sich gebärmutterschleimhautähnliches Gewebe außerhalb der Gebärmutter ansiedelt. Schätzungsweise **10 bis 15 % der Personen im reproduktiven Alter sind davon betroffen.**
- Dieser Bericht untersucht, welche Empfehlungen internationale Leitlinien für Diagnostik, Behandlung und Versorgungsorganisation geben, wie die Endometriose-Versorgung in Wien von Patient:innen und Ärzt:innen erlebt wird und inwieweit die aktuelle Praxis den Leitlinien entspricht.
- Die Ergebnisse zeigen, dass die **medizinische Versorgung in Wien in zentralen Bereichen weitgehend leitlinienkonform** ist. Die durchschnittliche **Diagnosedauer** beträgt jedoch 9,7 Jahre und bislang wurden nur 28,3 % der Patient:innen an ein zertifiziertes Zentrum überwiesen. Herausforderungen bestehen vor allem bei der organisatorischen Einbettung der Versorgung.
- **Zentrale Empfehlungen:** ein abgestufter Versorgungspfad mit klaren Zuweisungskriterien, eine frühere Erkennung durch bessere Fortbildung in der Grundversorgung, strukturierte interdisziplinäre Zusammenarbeit sowie standardisierte Patient:inneninformation und Qualitätsmonitoring.
- Die **Evidenz** zur Endometriose-Versorgung, sowohl klinisch als auch organisatorisch, ist insgesamt **begrenzt**.

Hintergrund/Problemstellung

Endometriose ist eine chronische, gutartige Erkrankung, bei der sich gebärmutterschleimhautähnliches Gewebe außerhalb der Gebärmutter ansiedelt. Sie betrifft schätzungsweise 10-15 % aller Personen im reproduktiven Alter. Zu den Leitsymptomen zählen unter anderem schmerzhafte Regelblutungen, chronische Unterbauchschmerzen, Schmerzen beim Geschlechtsverkehr und Unfruchtbarkeit. Die Symptome sind oft unspezifisch und individuell sehr unterschiedlich. Zudem korreliert die Symptomschwere nicht notwendigerweise mit dem Ausmaß der Erkrankung. Beides kann dazu beitragen, dass Endometriose erst spät erkannt und eine angemessene Behandlung verzögert eingeleitet wird. Für Betroffene bedeutet das oft jahrelange Schmerzen und psychische Belastung, mit entsprechenden Folgekosten für Gesundheitssystem und Gesellschaft.

In Österreich geben 6,4 % der menstruierenden Personen zwischen 14 und 60 Jahren an, bereits eine Endometriose-Diagnose erhalten zu haben. Aufgrund einer vermutlich hohen Dunkelziffer dürfte die tatsächliche Prävalenz jedoch höher liegen; schätzungsweise könnten bis zu 300.000 Personen betroffen sein. Bis zur Diagnosestellung vergehen laut einer Erhebung von 2024 im Durchschnitt 6,6 Jahre. Eine mögliche Ursache für diese Verzögerung liegt in der Struktur der Versorgung: Während der Zugang zu gynäkologischer Grundversorgung in Österreich niederschwellig ist, fehlen standardisierte Zuweisungswege zu spezialisierter Versorgung weitgehend. Österreich verfügt aktuell über 15 zertifizierte Endometriose-Zentren, davon vier in Wien.

Ziel dieses Berichts war es, die Versorgung von Endometriose-Patient:innen in Wien anhand aktueller internationaler evidenzbasierter Leitlinien zu bewerten. Der Vergleich zwischen den Leitlinienempfehlungen und der bestehenden Versorgung sowie die Einbeziehung der Perspektiven von Patient:innen und Gesundheitsdienstleister:innen ermöglichten die Identifizierung möglicher Versorgungslücken und ungedeckter Bedürfnisse.

Der vorliegende Bericht geht folgenden drei Forschungsfragen nach:

- Welche evidenzbasierten Empfehlungen zu Diagnostik und Therapie enthalten aktuelle internationale Leitlinien, und welche Versorgungsstrukturen beschreiben sie?
- Wie ist die aktuelle Versorgungsstruktur in Wien und welche Versorgungsdefizite und Bedürfnisse sehen Patient:innen und Gesundheitsdienstleister:innen in der Praxis?
- Inwieweit entspricht die Wiener Versorgungspraxis den internationalen Leitlinienempfehlungen?

Methoden

Zur Beantwortung der Forschungsfragen wurde ein Mixed-Methods-Design gewählt: Die Analyse basierte auf einer strukturierten Synopse von fünf internationalen Leitlinien (ESHRE, NICE, RANZCOG, AWMF, HSE) aus Europa und Australien. Zusätzlich wurden internationale Literatur zu Versorgungsmodellen sowie die Ergebnisse zweier anonymer Online-Befragungen unter praktizierenden Gynäkolog:innen (n=49) und Patient:innen mit Endometriose-Diagnose in Wien (n=53) berücksichtigt. Leitlinien wurden mittels manueller Suche identifiziert und ihre methodische Qualität mit dem AGREE II Tool (Appraisal of Guidelines for Research and Evaluation II) bewertet. Die Fragebögen wurden eigens für diesen Bericht entwickelt, da keine geeigneten standardisierten Instrumente verfügbar waren. Die Erhebung lief über einen Zeitraum von rund drei Monaten. Die quantitativen Daten wurden deskriptiv, die qualitativen Freitextantworten inhaltsanalytisch ausgewertet. Anschließend wurden die empirischen Ergebnisse den Leitlinienempfehlungen gegenübergestellt.

Ergebnisse

Leitliniensynopse

Keine der fünf Leitlinien erreichte in allen sechs AGREE-II-Domänen durchgehend hohe Qualität. Vier wurden als moderat, eine als niedrig bewertet. Stärken zeigten sich bei der Zielsetzung, der Einbindung von Interessengruppen und der verständlichen Darstellung. Schwächer und uneinheitlicher fielen die Bewertungen im Hinblick auf die Anwendbarkeit (z. B. konkrete Umsetzungshilfen) und redaktionelle Unabhängigkeit aus.

Trotz unterschiedlicher Bewertungssysteme und eingeschränkter Vergleichbarkeit der Leitlinien zeigte sich in zentralen klinischen Bereichen ein breiter Konsens, der teilweise durch eine gute Evidenzlage gestützt wurde. Bei der nicht-invasiven Diagnostik und der stufenweisen Behandlung waren die Empfehlungen weitgehend einheitlich. Dazu zählen insbesondere der transvaginale Ultraschall als Bildgebung erster Wahl, der Verzicht auf den Tumormarker CA-125 zur Diagnosestellung, die Erkenntnis, dass negative Bildbefunde Endometriose nicht ausschließen, hormonelle Erstlinientherapie bei Schmerzen sowie ein selektiver statt eines routinemäßigen Einsatzes von Laparoskopie und Chirurgie. Bei komplexeren Fragestellungen, etwa zu Zeitpunkt und Rolle chirurgischer Eingriffe, Fertilitätserhalt und Behandlung vor assistierter Reproduktion, waren die Empfehlungen heterogener und die Evidenz häufig unsicherer. Eine individualisierte Behandlung unter Berücksichtigung der reproduktiven Ziele und der Präferenzen der Patient:innen wurde durchgängig betont.

Die Empfehlungen zur Organisation der Versorgung waren deutlich weniger konkret. Zwar erkannten alle Leitlinien Endometriose als chronische Erkrankung an, die eine koordinierte, langfristige und multidisziplinäre Versorgung erfordert. Konkrete Vorgaben zu Zuweisungswegen, Zuständigkeiten, Kriterien für Fachzentren, multidisziplinären Strukturen, Qualitätssicherung, Fortbildung und Nachsorge blieben jedoch häufig allgemein.

Auch die zusätzliche Literatur zeigte erhebliche Unterschiede zwischen einzelnen Ländern und Versorgungsmodellen, insbesondere bei Versorgungsstufen, Zertifizierung und Überweisungsregelungen. Komplexe Fälle wurden häufig auch außerhalb ausgewiesener Fachabteilungen behandelt. Auch Patient:inneninformation und gemeinsame Entscheidungsfindung waren nicht durchgängig in die Versorgungspfade integriert, und es gab nur begrenzte Evidenz für eine strukturierte Rehabilitation.

Empirische Befunde aus Wien

Die Befragung von Patient:innen (N=53) weist auf lange und häufig fragmentierte Diagnosewege hin. Im Durchschnitt vergingen 9,7 Jahre bis zur Diagnose, und die meisten Befragten hatten zuvor mindestens drei Ärzt:innen konsultiert. Am häufigsten erfolgte die Diagnose in nicht spezialisierten gynäkologischen Praxen. Nur 28 % der Befragten wurden nach der Diagnose an ein zertifiziertes Zentrum überwiesen. Viele Patient:innen berichteten zudem, mit ihren Beschwerden wiederholt nicht ausreichend ernst genommen worden zu sein. Die Belastung war erheblich: 90,6 % berichteten von Auswirkungen auf ihre psychische Gesundheit, und 88,7 % gaben nicht erstattete Kosten an.

Die Befragung der Gynäkolog:innen (N=49) deutete in zentralen klinischen Bereichen auf eine weitgehend leitlinienkonforme Versorgungspraxis hin. Demgegenüber waren strukturierte Versorgungsprozesse deutlich weniger etabliert: Lediglich 16,3 % der Befragten berichteten von einem formal dokumentierten Versorgungspfad, 30,6 % von einer strukturierten interdisziplinären Zusammenarbeit, und 18,4 % waren an einem zertifizierten Endometriose-Zentrum tätig.

Die Ergebnisse stammen jedoch aus einer explorativen Querschnittserhebung mit vergleichsweise kleinen Stichproben, und sind daher als Hinweise auf Versorgungsmuster und mögliche Lücken, nicht als repräsentative Schätzung für Wien, zu interpretieren.

Leitlinien-Praxis-Abgleich

Der Abgleich zeigt insgesamt ein überwiegend positives Bild: In zentralen klinischen Bereichen, Ultraschall als Bildgebung erster Wahl, hormonelle Erstlinientherapie und zurückhaltender Einsatz von Chirurgie, stimmt die Wiener Praxis weitgehend mit den Leitlinien überein, vor allem dort, wo diese klare und konsistente Empfehlungen geben. Eine mögliche Diskrepanz betrifft den berichteten Einsatz von CA-125, von dem alle fünf Leitlinien einheitlich abraten. Allerdings erfasste die Befragung den konkreten klinischen Anlass nicht, sodass ein Teil davon der Abklärung auffälliger Ovarialbefunde statt der Endometriose-Diagnostik selbst gelten könnte. Weitere Lücken betreffen weniger einzelne klinische Entscheidungen als die organisatorische Einbettung der Versorgung, insbesondere Zuweisung, spezialisierte und interdisziplinäre Versorgung sowie Information und Entscheidungsfindung. Diese Bereiche lassen sich nur eingeschränkt als Abweichung einordnen, da die Leitlinien dazu meist allgemeine Ziele, aber keine konkreten Standards vorgeben, ein Muster, das sich auch in der internationalen Literatur zu Versorgungsmodellen wiederfindet. Da dieser Abgleich auf einer qualitativen Einschätzung beruht und Empfehlungsstärke sowie Evidenzsicherheit nicht formal gewichtet wurden, sind die berichteten Übereinstimmungen und Abweichungen als Gesamttendenz und nicht als exakte Kennzahl zu verstehen.

Schlussfolgerungen und Empfehlungen

Die Wiener Endometriose-Versorgung entspricht in zentralen diagnostischen und therapeutischen Aspekten weitgehend den internationalen Leitlinienempfehlungen. Gleichzeitig bestehen auch in der klinischen Versorgung relevante Evidenzunsicherheiten und teilweise heterogene Empfehlungen. Verbesserungsbedarf zeigt sich vor allem auf organisatorischer Ebene, insbesondere bei den Diagnosewegen, der Anbindung an spezialisierte Zentren, der strukturierten multidisziplinären Zusammenarbeit sowie im Hinblick auf Information und Einbindung der Patient:innen in Entscheidungen. Vergleichbare Muster finden sich auch in der internationalen Literatur. Die bestehenden Herausforderungen sind damit nicht allein ein Problem in Wien, sondern spiegeln auch wider, dass internationale Leitlinien die organisatorische Ausgestaltung einer guten Endometriose-Versorgung bislang nur begrenzt konkretisieren und insbesondere zur wirksamen Gestaltung und Umsetzung von Versorgungsmodellen noch relevante Evidenzlücken bestehen.

Als wichtige Ansatzpunkte für Verbesserungen nannten die befragten Gynäkolog:innen klarere Überweisungswege, eine Stärkung von Aus- und Weiterbildung sowie ausreichende spezialisierte Versorgungskapazitäten. Insgesamt legen die Ergebnisse insbesondere einen besser abgestimmten, strukturierten Versorgungspfad mit klaren Zuständigkeiten sowie eine stärkere Vernetzung der beteiligten Versorgungsbereiche nahe. Darüber hinaus erscheinen eine frühere Diagnosestellung, eine stärkere interdisziplinäre Zusammenarbeit sowie eine konsistentere Information, psychosoziale Unterstützung und Einbindung der Patient:innen als relevante Handlungsfelder. Ergänzend könnten lokale Qualitätsstandards und eine systematische Evaluation der Versorgung die Umsetzung unterstützen.

Summary

Key messages

- Endometriosis is a chronic, benign condition in which endometrium-like tissue settles outside the uterus. An estimated 10 to 15% of individuals of reproductive age are affected.
- This report examines which recommendations international guidelines provide for diagnosis, treatment and the organisation of care, how endometriosis care in Vienna is experienced by patients and doctors, and to what extent current practice aligns with the guidelines.
- The results show that medical care in Vienna is largely guideline concordant in core areas. However, the average diagnostic delay is 9.7 years, and to date only 28.3% of patients have been referred to a certified centre. Challenges exist primarily in the organisational embedding of care.
- Key recommendations include a tiered care pathway with clear referral criteria, earlier recognition through improved training in primary care, structured interdisciplinary collaboration, and standardised patient information and quality monitoring.
- The evidence on endometriosis care, both clinical and organisational, remains limited overall.

Background/Problem statement

Endometriosis is a chronic, benign condition in which endometrium-like tissue settles outside the uterus. It affects an estimated 10 to 15% of all individuals of reproductive age. Key symptoms include painful periods, chronic pelvic pain, pain during intercourse, and infertility, among others. Symptoms are often non-specific and vary considerably between individuals. In addition, symptom severity does not necessarily correlate with the extent of the disease. Both factors can contribute to endometriosis being recognised late and appropriate treatment being delayed. For those affected, this often means years of pain and psychological burden, with corresponding follow-on costs for the healthcare system and society.

In Austria, 6.4% of menstruating individuals aged 14 to 60 report having already received an endometriosis diagnosis. Because a presumably high number of cases remain undiagnosed, the true prevalence is likely to be higher, with an estimated up to 300,000 individuals possibly affected. According to a 2024 survey, an average of 6.6 years passes before diagnosis. One possible reason for this delay lies in the structure of care. While access to general gynaecological care in Austria is relatively straightforward, standardised referral pathways to specialised care are largely lacking. Austria currently has 15 certified endometriosis centres, four of which are in Vienna.

The aim of this report was to assess the care of endometriosis patients in Vienna against current international evidence-based guidelines. Comparing guideline recommendations with existing care, together with the inclusion of the perspectives of patients and healthcare providers, made it possible to identify potential gaps in care and unmet needs.

This report addresses the following three research questions:

- What evidence-based recommendations on diagnosis and treatment do current international guidelines provide, and what care structures do they describe?
- What is the current care structure in Vienna, and what care deficits and needs do patients and healthcare providers identify in practice?
- To what extent does care practice in Vienna correspond to international guideline recommendations?

Methods

A mixed-methods design was used to address the research questions. The analysis was based on a structured synopsis of five international guidelines (ESHRE, NICE, RANZCOG, AWMF, HSE) from Europe and Australia. In addition, international literature on care models and the results of two anonymous online surveys among practising gynaecologists (n=49) and patients with an endometriosis diagnosis in Vienna (n=53) were considered. Guidelines were identified through manual searches, and their methodological quality was assessed using the AGREE II tool (Appraisal of Guidelines for Research and Evaluation II). The questionnaires were developed specifically for this report, as no suitable standardised instruments were available. Data collection took place over a period of approximately three months. Quantitative data were analysed descriptively, and qualitative free-text responses were analysed using content analysis. The empirical results were then compared against the guideline recommendations.

Results

Guideline synopsis

None of the five guidelines achieved consistently high quality across all six AGREE II domains. Four were rated as moderate and one as low. Strengths were evident in scope and purpose, stakeholder involvement, and clarity of presentation. Ratings were weaker and more inconsistent with regard to applicability, for example concrete implementation tools, and editorial independence.

Despite differing appraisal systems and limited comparability between guidelines, a broad consensus emerged in core clinical areas, supported by a sound evidence base. Recommendations were largely consistent for non-invasive diagnosis and stepwise management. These include transvaginal ultrasound as the first-choice imaging method, avoidance of the tumour marker CA-125 for diagnosis, recognition that negative imaging findings do not rule out endometriosis, hormonal treatment as first-line therapy for pain, and a selective rather than routine use of laparoscopy and surgery. For more complex issues, such as the timing and role of surgical intervention, fertility preservation, and treatment prior to assisted reproduction, recommendations were more heterogeneous and the evidence often less certain. Individualised treatment, taking into account patients' reproductive goals and preferences, was consistently emphasised.

Recommendations on the organisation of care were considerably less concrete. Although all guidelines recognised endometriosis as a chronic condition requiring coordinated, long-term, and multidisciplinary care, concrete guidance on referral pathways, responsibilities, criteria for specialist centres, multidisciplinary structures, quality assurance, training, and follow-up care often remained general.

The additional literature likewise showed considerable differences between countries and care models, particularly regarding levels of care, certification, and referral arrangements. Complex cases were frequently managed outside designated specialist departments. Patient information and shared decision-making were also not consistently embedded in care pathways, and evidence for structured rehabilitation remained limited.

Empirical findings from Vienna

The patient survey (N=53) points to long and often fragmented diagnostic pathways. On average, 9.7 years passed before diagnosis, and most respondents had previously consulted at least three doctors. Diagnosis most commonly occurred in non-specialised gynaecological practices. Only 28% of respondents were referred to a certified centre following diagnosis. Many patients also reported repeatedly feeling that their symptoms were not taken sufficiently seriously. The burden was considerable. 90.6% reported effects on their mental health, and 88.7% reported non-reimbursed costs.

The survey of gynaecologists (N=49) indicated a largely guideline concordant practice in core clinical areas. In contrast, structured care processes were considerably less well established. Only 16.3% of respondents reported following a formally documented care pathway, 30.6% reported structured interdisciplinary collaboration, and 18.4% worked at a certified endometriosis centre.

However, these results derive from an exploratory cross-sectional survey with comparatively small samples, and should therefore be interpreted as indications of care patterns and possible gaps, rather than as a representative estimate for Vienna.

Guideline practice comparison

The comparison shows an overall predominantly positive picture. In core clinical areas, namely ultrasound as the first-choice imaging method, hormonal first-line therapy, and the restrained use of surgery, practice in Vienna aligns largely with the guidelines, particularly where these provide clear and consistent recommendations. One possible discrepancy concerns the reported use of CA-125, which all five guidelines uniformly advise against. However, the survey did not capture the specific clinical context of testing, so some of this use may relate to the work-up of suspicious ovarian findings rather than endometriosis diagnostics itself. Further gaps concern not so much individual clinical decisions as the organisational embedding of care, particularly referral, specialised and interdisciplinary care, and information and decision-making. These areas can only be classified as deviations to a limited extent, since guidelines generally provide only broad goals rather than concrete standards in this regard, a pattern also found in the international literature on care models. As this comparison is based on a qualitative assessment, and recommendation strength and certainty of evidence were not formally weighted, the reported areas of concordance and divergence should be understood as an overall tendency rather than as an exact metric.

Conclusions and recommendations

Endometriosis care in Vienna largely corresponds to international guideline recommendations in core diagnostic and therapeutic aspects. At the same time, relevant evidence uncertainties and, in part, heterogeneous recommendations also exist within clinical care itself. The need for improvement is evident primarily at the organisational level, particularly with regard to diagnostic pathways, links to specialised centres, structured multidisciplinary collaboration, and patient information and involvement in decision-making. Comparable patterns are also found in the international literature. The existing challenges are therefore not solely a problem specific to Vienna. They also reflect the fact that international guidelines to date only provide limited concrete guidance on the organisational design of good endometriosis care, and that relevant evidence gaps remain, particularly regarding the effective design and implementation of care models.

The gynaecologists surveyed identified clearer referral pathways, strengthened education and training, and sufficient specialised care capacity as important starting points for improvement. Overall, the results in particular suggest a better coordinated, structured care pathway with clear responsibilities, as well as stronger networking between the care sectors involved. In addition, earlier diagnosis, stronger interdisciplinary collaboration, and more consistent information, psychosocial support, and involvement of patients appear to be relevant areas for action. Local quality standards and systematic evaluation of care could further support implementation.

1 Background

1.1 Endometriosis

1.1.1 Definition and Pathophysiology

Endometriosis is a chronic, benign condition characterised by the growth of endometrium-like tissue outside the uterus. It is among the most common benign conditions affecting menstruating individuals of reproductive age [1, 2].

The presence of ectopic, endometrium-like tissue most commonly affects sites within the pelvis, including the peritoneum and ovaries, but may also arise in extrapelvic sites throughout the body. Deep infiltrating endometriosis (DIE) is characterised by nodular lesions that may involve the bowel, bladder, or vagina. Scar endometriosis following surgical procedures represents a rare manifestation of the disease [1, 3]. Adenomyosis is not addressed in this report.

The pathogenesis of endometriosis is complex and multifactorial. Several pathways have been proposed, including retrograde menstruation, benign metastasis of endometrial cells, immune dysregulation, coelomic metaplasia, hormonal imbalance, stem cell involvement, and epigenetic influences. Still, the exact mechanisms underlying the development of endometriosis remain incompletely understood [4].

Ectopic tissue responds to cyclical hormonal fluctuations and undergoes bleeding concurrent with menstruation. As this blood cannot drain, it gives rise to local inflammatory responses, adhesions, fibrosis, or cyst formation in the surrounding tissue [3].

At the molecular level, the disease is characterised by a persistent inflammatory peritoneal milieu, altered immune responses, and hormonal dysregulation with oestrogen dominance and progesterone resistance, partly driven by epigenetic changes. Oxidative stress and activation of intracellular signalling pathways further promote lesion persistence, impaired apoptosis, and, particularly in ovarian involvement, progressive reduction of ovarian reserve [5].

The biological heterogeneity of endometriosis is reflected in its diverse and variable clinical presentation.

1.1.2 Epidemiology

Overall, endometriosis is estimated to affect 10-15% of individuals of reproductive age, with the true prevalence likely being underreported [6, 7]. Several factors complicate the diagnosis, including diagnostic delay, variability in lesion appearance, incomplete histological verification and historical reliance on surgical confirmation [8]. In addition, symptom normalisation, limited awareness among both patients and healthcare providers, and the heterogeneous, often non-specific presentation of this “chameleon” disease may further contribute to the underrecognition of its true burden [8, 9]. Among patients presenting with chronic pelvic pain and/or unfulfilled desire for pregnancy, endometriosis is identified in 35-50% of cases [7]. Furthermore, the condition is not restricted to the reproductive years but may also manifest in adolescents and postmenopausal individuals [7, 10].

gutartige chronische Erkrankung im reproduktiven Alter

Ektope Gebärmutter-schleimhaut-ähnliche Läsionen

pelvine & extrapelvine Manifestationen

Pathogenese nicht abschließend geklärt

zyklische Blutung außerhalb der Gebärmutter

Entzündungs-, Immun- & Hormonmechanismen

hohe Prävalenz (10-15 % aller Frauen) bei unklarer Dunkelziffer

vielfältige Symptomatik erschwert Diagnose

1.1.3 Classification and Subtypes

Classification of Endometriosis

Several classification systems are used to describe endometriosis, each addressing different aspects of the disease. The revised American Society for Reproductive Medicine classification (rASRM) is the most widely used system and categorises disease extent into four stages based on surgical findings, including lesion size, location, and adhesions: stage I (minimal), stage II (mild), stage III (moderate), and stage IV (severe). However, it correlates only weakly with symptoms such as pain or infertility and does not adequately capture DIE [11].

The #Enzian classification was developed to address this gap in capturing DIE, offering a more detailed compartmental description of DIE to support preoperative planning, though it remains more complex and less widely used. The Endometriosis Fertility Index (EFI) serves a different purpose, combining clinical and surgical findings to calculate a score from 0 to 10 that estimates the likelihood of spontaneous pregnancy over time following surgery. Additionally, the Aymerican Association of Gynaecological Laparoscopists (AAGL) is currently developing a new system to more comprehensively integrate clinically relevant aspects. Overall, however, no single classification fully captures all characteristics of the disease [11].

**rASRM als am häufigsten
verwendetes
Klassifikationssystem**

**ENZIAN zur detaillierten
Erfassung von DIE;
EFI für Fertilitätsprognose**

**keine Klassifikation erfasst
die Erkrankung vollständig**

Subtypes of Endometriosis

Endometriosis can present in several subtypes, which are defined based on the location and pathological characteristics of the lesions. An international working group consisting of the AAGL, the European Society for Gynaecological Endoscopy (ESGE), the European Society of Human Reproduction and Embryology (ESHRE) and the World Endometriosis Society (WES) proposed a classification to describe these different manifestations. The main subtypes are summarised in Table 1-1 below [12]:

**internationale
Klassifikation der Subtypen**

Table 1-1: Subtypes of endometriosis adapted from International Working Group of AAGL, ESGE, ESHRE and WES [12]

Subtype	Pathological Definition
Peritoneal/superficial endometriosis	Endometrium-like tissue deposits on the peritoneal surface.
Ovarian endometriotic cyst (endometrioma)	Endometrium-like tissue forming cysts in the ovary, containing dark blood-filled material ("chocolate cysts").
Deep endometriosis	Nodular endometrium-like lesions located on or beneath the peritoneal surface, often with fibrosis and involvement of adjacent structures.
Bowel endometriosis	Endometriosis within the bowel wall (e.g., rectosigmoid).
Bladder endometriosis	Endometriosis affecting the muscle or mucosal layers of the bladder.
Extra-abdominal endometriosis	Endometrium-like tissue located outside the abdominal cavity.
Iatrogenic endometriosis	Lesions caused by the surgical transplantation of endometrial tissue.
Adhesions	Fibrous bands that can form as a result of the inflammatory process associated with the disease.

Abbreviations: AAGL ... American Association of Gynaecological Laparoscopists, ESGE ... European Society of Gastrointestinal Endoscopy, ESHRE ... European Society of Reproduction and Embryology, WES ... World Endometriosis Society

1.1.4 Clinical Presentation

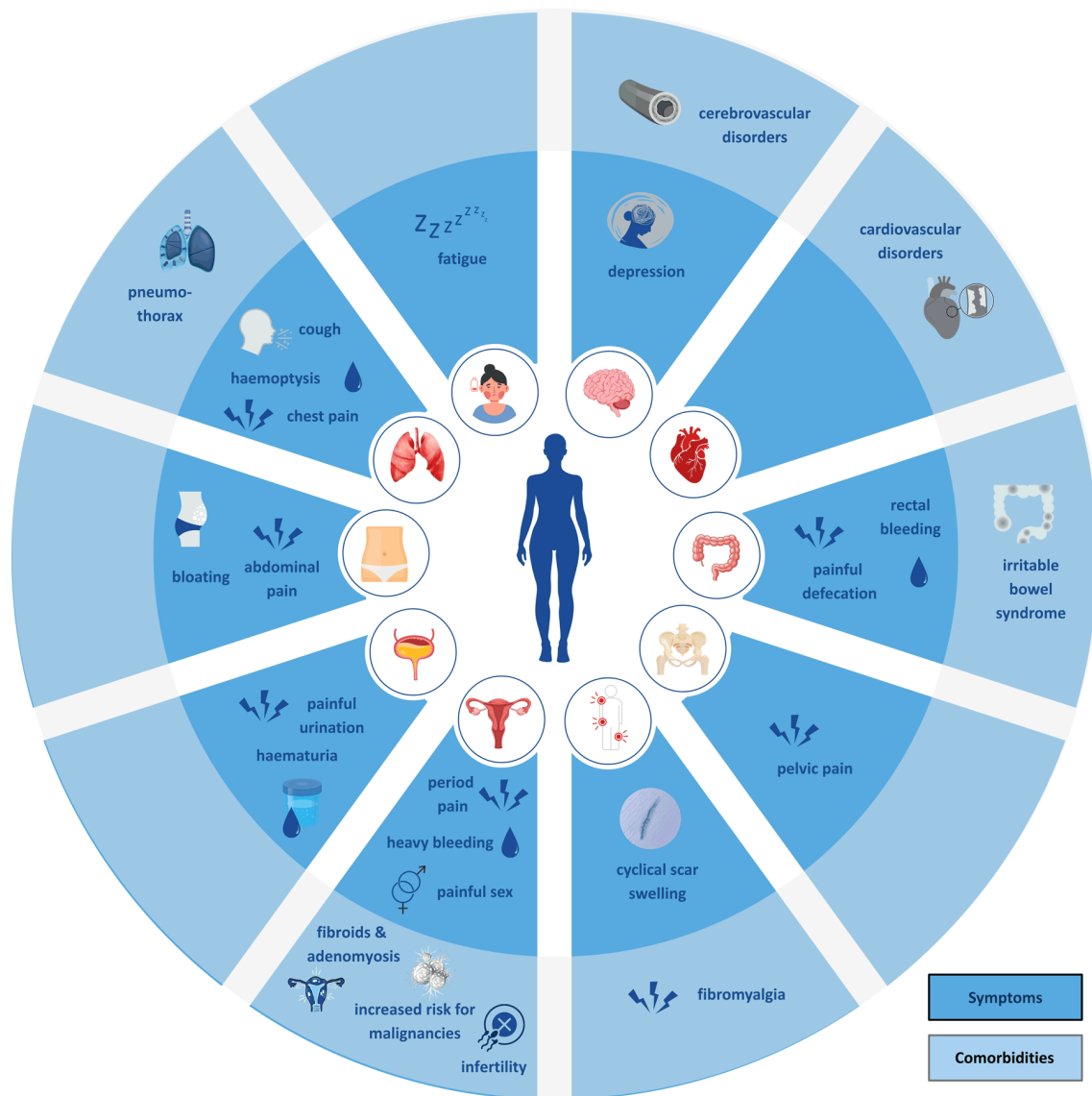


Figure 1-1: Symptoms and Comorbidities of Endometriosis (Own illustration)

Symptoms vary considerably depending on the location and extent of the lesions, ranging from absent or minimal complaints to severe pain or functional impairment [3]. The severity of anatomical lesions does not always correlate with the clinical presentation; some patients with minimal visible endometriosis experience severe symptoms, while others with extensive disease may have few or no symptoms [13].

The most common symptoms include painful menstrual bleeding (dysmenorrhoea), chronic cyclical and/or non-cyclical pelvic pain and pain during or after sexual intercourse (dyspareunia). Menstrual disturbances, including heavy or irregular bleeding may occur, and infertility affects a large percentage of affected individuals. Depending on disease location, patients may also experience gastrointestinal and urinary symptoms such as bloating, painful defecation

keine klare Korrelation zwischen Erkrankungsausmaß & Symptomen

Leitsymptome: Schmerz & Infertilität

zyklische gastrointestinale & urogenitale Beschwerden ...

(dyschezia), painful micturition (dysuria) and rectal bleeding or blood in urine (haematuria). Extrapelvic involvement can manifest as cyclical scar swelling or pain, cyclical cough, chest pain or coughing up blood (haemoptysis), cyclical pulmonary complications (pneumothorax), and any other cyclical complaints [14]. Fatigue is frequently reported and additionally, endometriosis may have psychological sequelae, including depression [3]. Considered a multisystem disorder, individuals with endometriosis have an increased likelihood of presenting with comorbid chronic pain conditions such as fibromyalgia and irritable bowel syndrome, as well as other benign gynaecological disorders including uterine fibroids and adenomyosis. They also face a higher risk of subsequently developing certain malignancies, particularly ovarian cancer, in addition to autoimmune diseases, early menopause, and cerebrovascular and cardiovascular disorders [13]. Figure 1-1 provides a schematic overview of the symptoms and comorbidities associated with endometriosis.

**... Müdigkeit,
psychische Belastung
& Komorbiditäten**

1.1.5 Diagnosis and Treatment

Endometriosis is often suspected based on the characteristic symptoms discussed earlier. Diagnostic assessment may include clinical evaluation, transvaginal ultrasound (TVUS), magnetic resonance imaging (MRI) and laparoscopy, although laparoscopy is not always necessary to establish a diagnosis (see chapter 1.1.7, for Austria-specific diagnostic and reimbursement provisions). Normal findings on diagnostic investigations do not exclude endometriosis, and diagnosis and initiation of treatment may be based on the clinical presentation [13, 15].

**Diagnostik zunehmend
bildgebungsbasiert statt
laparoskopisch**

**Normalbefund schließt
Endometriose nicht aus**

Treatment of endometriosis is multifaceted, reflecting the complex nature of the disease.

Management of endometriosis-associated pain includes both medical and surgical approaches. First-line medical treatment primarily consists of hormonal therapies (combined hormonal contraceptives, progestins, or GnRH agonists/antagonists) aimed at suppressing ovarian hormone production, thereby reducing inflammation and pain; Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) are also commonly used, despite limited evidence of efficacy [13].

**hormonelle Therapie als
First-Line-Behandlung**

Surgical management, particularly laparoscopic excision or ablation of endometriotic lesions, is generally considered in patients with severe symptoms, deep infiltrating endometriosis, or anatomical distortion [13]. Infertility management relies primarily on surgery and assisted reproductive technology (ART), as hormonal suppression therapies control symptoms but do not improve fertility [13].

**Operative Therapie
v. a. bei komplexeren
Fällen und Infertilität**

In addition to conventional medical treatment, non-pharmacological approaches such as physiotherapy, psychological interventions, transcutaneous electrical nerve stimulation (TENS), and dietary measures may support symptom management and quality of life. However, the evidence base for these approaches remains limited [16-18].

**diverse komplementäre
Therapieansätze bei
Endometriose**

1.1.6 Impact and Disease Burden

Although endometriosis is a benign condition, its chronic course and frequent comorbidities result in substantial medical and societal significance. The Endo-Cost study emphasises the magnitude of endometriosis as a major health issue, revealing that the economic burden of the disease rivals that of well-recognised chronic disorders such as diabetes mellitus. In this large international multi-centre analysis of 909 individuals, the mean annual total cost per patient was estimated at €9,579 (95% CI €8,559-€10,599), with indirect costs attributable to productivity loss (€6,298) approximately twice as high as direct healthcare costs (€3,113) [19].

hohe medizinische & gesellschaftliche Relevanz

hohe indirekte Kosten durch Produktivitätsverlust

1.1.7 Endometriosis in Austria

In Austria, 6.4% of menstruating individuals aged 14 to 60 years report having a diagnosis of endometriosis, of whom 67% are premenopausal and 28% are peri- or postmenopausal. A further 4.4% suspect they may have the condition without having received a diagnosis [10]. However, the actual prevalence is likely underestimated due to the high number of unreported cases, with up to 300,000 individuals estimated to be affected [20]. Overall, data on endometriosis in Austria are generally very limited, with little representative data on risk factors or the healthcare situation [21].

Österreich: geschätzt 6 % von menstruierenden Personen betroffen

Furthermore, nearly one-third (31.3%) of potentially affected individuals currently have no knowledge of endometriosis as a disease entity. The average time to diagnosis in Austria is currently 6.6 years [10].

geringes Krankheitsbewusstsein & langer Diagnoseweg

In Vienna, endometriosis was documented as the primary diagnosis in 655 cases and as a secondary diagnosis in 738 cases during hospital stays in 2023 [22].

Endometriosis care in Austria is characterised by relatively open access to specialist services. General practitioners do not function as gatekeepers, and patients commonly seek care directly from gynaecologists, who assume primary responsibility for diagnosis and management [3, 23]. Care is therefore largely provided in outpatient settings or hospital departments. In more complex cases, referral to certified endometriosis centres may occur; however, pathways to specialist care are not consistently structured or embedded in a standardised referral system [3].

niederschwelliger Zugang zur gynäkologischen Versorgung; keine standardisierte Zuweisung zu spezialisierter Versorgung

In Austria, the Austrian Health Insurance Fund (Österreichische Gesundheitskasse (ÖGK)) states that the diagnosis of endometriosis should be established by a specialist in gynaecology and obstetrics or at a specialised endometriosis centre, with TVUS as the primary diagnostic modality and MRI as a second-line modality; the two methods are considered equivalent. Importantly, surgical confirmation by laparoscopy is not required as a prerequisite for hormonal treatment in the Austrian healthcare context. The ÖGK explicitly recognises hormonal treatment of endometriosis as a health insurance benefit and states that, where clinically indicated, certain hormonal preparations are freely prescribable within the Green section of the Austrian Reimbursement Code [24].

ÖGK: TVUS als primäre Diagnostik, Laparoskopie nicht erforderlich

Medical training does not formally include endometriosis as a distinct element of gynaecology specialist education, and expertise is primarily acquired through clinical exposure and surgical treatment in hospitals as well as in specialised centres [25].

Facharztausbildung: Endometriose kein eigener Ausbildungsinhalt

According to EuroEndoCert, Austria has 15 certified endometriosis facilities, comprising eight certified endometriosis centres (three in Vienna), four certified endometriosis clinics (none in Vienna), and three certified endometriosis practices (one in Vienna) [26].

**15 zertifizierte
Einrichtungen in
Österreich & Wien**

2 Research Question and Project Aim

This report, proposed by the Frauengesundheitsbüro der Stadt Wien (Vienna Women's Health Programme), aims to systematically identify and synthesise current international guideline recommendations on the diagnosis and treatment of endometriosis, consider the evidence base underlying these recommendations, and identify evidence-based interventions and care pathways applicable to clinical practice. In addition, a non-representative survey among patients and gynaecologists in Vienna was conducted to capture the current care structure, along with perceived strengths, gaps, and unmet needs in everyday practice. Finally, the guideline-derived recommendations were systematically compared against this cross-section of real-world care in Vienna, in order to determine which recommendations are already implemented in practice, which aspects of care function well, and where potential for improvement exists.

The report is structured around the following research questions:

- RQ1:** 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?
- RQ2:** What is the current care structure in Vienna, and which gaps in care and unmet needs do patients and healthcare providers identify in practice?
- RQ3:** To what extent does current care practice in Vienna align with international guideline recommendations and recommendations for care pathways?

Berichtsziel:

Vergleich Leitlinien und Versorgungspraxis in Wien

Identifikation von Versorgungslücken und Verbesserungspotenzialen

Forschungsfragen

3 Methods

3.1 General Overview

A mixed-methods approach was employed to address the research questions, combining a structured synopsis of international clinical guidelines and organisational care models for endometriosis with an empirical investigation conducted in Vienna.

For **RQ1**, a structured manual search for international guidelines and models of endometriosis care was undertaken.

Furthermore, an additional manual search was conducted to identify literature on existing care structures. The comparative analysis of endometriosis care organisation in five high-income countries by Leroy et al. (2025) [27] served as the analytical foundation for this component.

For **RQ2**, a cross-sectional empirical study was conducted among healthcare providers and patients in Vienna. As part of this empirical component, surveys were developed to explore clinical management, experiences of care and organisational aspects of endometriosis care within the local healthcare setting.

For **RQ3**, a narrative comparative analysis was conducted by mapping findings from the empirical surveys against international guideline recommendations and describing care pathway models.

The research project was pre-registered on the Open Science Framework (OSF) platform under the registration 10.17605/OSF.IO/KF946.

Mixed-Methods-Ansatz

FF1:
Manuelle Suche nach Leitlinien & Versorgungsmodellen

FF2:
Empirische Analyse der Versorgungspraxis in Wien

FF3:
Narrativer Abgleich von Evidenz & Versorgungspraxis

3.2 PICo and Literature Identification

PICo

The following Population-Interest/Phenomenon of Interest-Context (PICo) scheme (Table 3-1) guided the literature search and the final selection of the literature:

PICo

Table 3-1: PICo

Population	Individuals with a confirmed or suspected diagnosis of endometriosis Healthcare providers (e.g. gynaecologists, general practitioners, nursing staff, therapists) in the context of endometriosis care
Interest (Phenomenon of Interest)	Current diagnostic and therapeutic practice in endometriosis care, including referral pathways, multidisciplinary collaboration, patient information and involvement in decision-making, assessed against recommendations set out in current international clinical guidelines.
Context	The organisation and delivery of endometriosis care within the Viennese healthcare system, considered in relation to international guideline recommendations and the wider international literature on organisational models of endometriosis care.
Study design	Evidence-based guidelines and recommendations on care pathways combined with two cross-sectional online surveys
Countries	Selected Western countries with comparable healthcare systems
Languages	English, German

Abbreviations: GoR ... Grade of Recommendation, LoE ... Level of Evidence

Identification of Guidelines

Relevant clinical guidelines were identified through a manual search of the following databases and platforms:

- Guidelines International Network (GIN)
- TRIP Database
- Google Scholar

No strict publication date restrictions were applied; however, emphasis was placed on current and internationally recognised guidelines from healthcare systems comparable to the Austrian setting.

**Literatursuche
via Datenbanken &
manueller Handsuche**

Identification of Care Models

International care models were identified through structured manual searches and a supplementary literature review. Consideration was given to models implemented in countries with healthcare systems and organisational structures comparable to the Austrian context.

3.3 Quality Assessment of the Guidelines

The methodological quality of the included guidelines was assessed using the Appraisal of Guidelines for Research & Evaluation (AGREE II) instrument [28].

Assessments were conducted independently by two reviewers (LG, DG). The tool comprises 23 items organised into six domains [28]:

- **Domain 1. Scope and Purpose** is concerned with the overall aim of the guideline, the specific health questions, and the target population (items 1-3);
- **Domain 2. Stakeholder Involvement** focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users (items 4-6);
- **Domain 3. Rigour of Development** relates to the process used to gather and synthesise the evidence, the methods to formulate the recommendations, and to update them (items 7-14);
- **Domain 4. Clarity of Presentation** deals with the language, structure, and format of the guideline (items 15-17);
- **Domain 5. Applicability** pertains to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline (items 18-21); and
- **Domain 6. Editorial Independence** is concerned with the formulation of recommendations not being unduly biased by competing interests (items 22-23).

Each item is scored from one (strongly disagree) to seven (strongly agree), with domain scores calculated by summing all items within the respective domain. As the six domain scores are independent, they were not aggregated into a single overall quality score. Quality thresholds were defined by consensus across all six domains: guidelines scoring above 70% in all six domains were classified as high quality; those scoring above 70% in four to five domains as moderate quality; and those scoring above 70% in one to three domains as low quality.

**Leitlinienqualität anhand
von AGREE II bewertet**

**AGREE II umfasst
6 Qualitätsdomänen**

**Qualitätsschwellen
konsensbasiert festgelegt**

3.4 Data Extraction and Synthesis of Guidelines and Care Models

To manage the extensive landscape of endometriosis guidelines and healthcare models, predefined extraction categories covering diagnosis, treatment, referral, care organisation, and patient-centred care were applied to ensure systematic and consistent data synthesis. Additional literature was used to supplement guideline recommendations with further information on care structures, implementation approaches and organisational models, as these aspects are generally only addressed to a limited extent in clinical guidelines. The complete extraction framework is provided in the supplementary material.

**systematische Extraktion
zu Leitlinienempfehlungen
& Versorgungsorganisation**

Data extraction was divided into two components:

- **Guideline recommendations**, including strength of recommendation and level of evidence where available
- **Organisation and delivery of care**, covering system structure, certification of specialist centres, referral pathways and access to care, multidisciplinary care, quality assurance and professional training, and patient information and shared decision-making.

This included:

- **Guideline-based recommendations** pertaining to care structures and service delivery
- **Supplementary non-guideline papers** on healthcare organisation models and other relevant aspects of care delivery

Two authors (LG and DG) independently extracted data from their respective components, with each author's extractions subsequently verified by the other. A third author (ER) was consulted in cases of uncertainty or ambiguity. Results were summarised through a narrative synthesis and supplemented with tables and figures.

As guideline developers may use different methodological frameworks and grading systems, the methods used to classify certainty of evidence and strength of recommendations were extracted for each included guideline and assessed for comparability. The possibility of mapping these systems to a common framework for harmonisation was explored.

For the guideline synopsis, terminology was selected to reflect, as far as possible, the direction and strength of the original recommendations. More directive wording, such as "recommend", was used for strong or clearly directive recommendations, while more cautious wording, such as "suggest" or "emphasise", was used for weaker, conditional, consensus-based or lower-certainty recommendations. Guideline-specific details on recommendation strength and underlying certainty of evidence for key recommendations are provided in the accompanying tables.

3.5 Empirical Studies

To comprehensively assess the current state of endometriosis care in Vienna, including existing strengths and deficits, an empirical component was conducted alongside the manual literature search. This investigation was designed to capture both healthcare provider and patient perspectives on real-world care provision.

For this purpose, two independent cross-sectional studies were developed and implemented: one targeting healthcare providers and one targeting patients. Both studies were conducted as online surveys using the platform SoSci Survey (www.sosicisurvey.de). Both surveys were conducted over a period of approximately three months, from early April to the end of June. The questionnaires consisted of a combination of closed- and open-ended questions, enabling both quantitative and qualitative analyses. Emphasis was placed on capturing experiences, perceived barriers, and structural characteristics of care provision.

The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [29]. Both surveys were conducted anonymously. At no point was it possible for the research team to trace responses back to individual participants, thereby ensuring full confidentiality and compliance with data protection standards. Participation was entirely voluntary. Respondents could discontinue the survey at any time and had the option to skip any question they did not wish to answer.

Questionnaire Design

One of the authors developed the questionnaires, which were then reviewed, revised, and jointly finalised with the co-authors. Due to time constraints, no formal pretesting was conducted prior to data collection. Both questionnaires were based on the same underlying principle and were structured into thematic sections, capturing both the clinical standard of care (e.g., diagnostic and therapeutic procedures) and individual experiences (e.g., aspects perceived to function well, as well as identified deficits and challenges). Questions were predominantly multiple-choice, using both single- and multiple-response formats, and were complemented by open-ended questions to capture individual experiences as comprehensively as possible. Both questionnaires are provided in full in the Appendix.

Healthcare Provider Survey

The cross-sectional survey addressing providers was conducted among all practising gynaecologists in Vienna with a valid email address ($n=354$), including those working in group practices, individual practices, and private practice settings. A reminder email was sent approximately six weeks after the initial invitation to increase the response rate. Since the survey exclusively targeted expert participants and did not collect sensitive personal data, no ethics approval was required. The questionnaire assessed key aspects of endometriosis care, including the implementation of guideline recommendations in clinical practice, existing care structures, perceived barriers to care provision, interdisciplinary collaboration, and the perceived feasibility of implementing existing guideline recommendations in the current healthcare setting.

**empirische Erhebung
erfasst Patient:innen- &
Versorger:innen-
perspektiven**

**COREQ-orientierte
Berichterstattung;
Teilnahme anonym &
freiwillig**

**Versorger:innen-Survey
erfasst Umsetzung,
Barrieren &
Implementierbarkeit von
Leitlinienempfehlungen**

Patient Survey

Prior to data collection, an ethics application was submitted to the Ludwig Boltzmann Gesellschaft and received a positive assessment; the ethics approval document is provided in the Appendix. Participants were recruited through multiple channels, including professional networks, patient organisations and online platforms. A flyer containing a QR code linking to the survey was distributed to three self-help groups and to the gynaecologists contacted for the provider survey; six physiotherapists specialising in endometriosis were also asked to display the flyer in their waiting rooms. To lower the barrier to participation and reach a broader audience, the questionnaire was translated into four languages (English, Turkish, Bosnian/Croatian/Serbian, and Arabic). The questionnaire assessed key aspects of patients' experiences with endometriosis care, including the diagnostic pathway, treatment received, out-of-pocket costs, involvement in shared decision-making, and perceived gaps in information and support, as well as the broader psychosocial impact of the condition on daily life.

**ethisch genehmigte
Patient:innenbefragung
mit mehrsprachigem
Zugang**

Data Analysis Empirical Studies

Data analysis was conducted using Microsoft Excel. Quantitative data derived from closed-ended questions were analysed descriptively using frequency distributions and percentages. Qualitative data from open-ended responses were analysed using qualitative content analysis following Mayring [30], including the development of a coding framework, systematic coding of responses, and categorisation into thematic groups. The findings are presented in aggregated form and supplemented by illustrative quotations. The coding process was documented for each survey in a structured Excel matrix.

**quantitative &
qualitative Auswertung
der Survey-Daten**

3.6 Assessment of Concordance with Guideline Recommendations

Findings from the clinician and patient surveys were compared with the guideline synopsis across key domains of diagnosis, treatment, referral, care organisation, and patient-centred care. Clinician-reported data reflected usual clinical and organisational practice, while patient-reported data provided complementary information on care received, communication, diagnostic pathways, treatment experiences, and access to care. As the two surveys captured different perspectives and constructs, differences between them were interpreted cautiously and were not assumed to represent direct contradictions.

**Gegenüberstellung von
Leitlinienempfehlungen
& Versorgungspraxis**

The comparison considered the overall direction, consistency, and specificity of recommendations across the included guidelines, the degree to which the corresponding survey item directly reflected the recommended practice or care process, and relevant limitations in comparability or clinical context. Evidence grading and strength of recommendation were not used to weight the concordance classifications. Although these were extracted and described in the guideline synopsis, differences in grading systems and methodological approaches, as well as heterogeneity in the underlying evidence supporting the recommendations, limited meaningful comparison across guidelines. Concordance assessments therefore focused primarily on the consistency and direction of guideline recommendations and their correspondence with the survey findings.

**Kriterien für die Bewertung
von Leitlinienkonformität**

Concordance was classified into the following categories:

- **Fully concordant:** Used where the relevant guidelines showed a clear and consistent overall direction and the available survey findings directly and consistently reflected that direction, with little or no contradictory information.
- **Broadly concordant:** Used where the guideline direction was sufficiently consistent to permit comparison and the overall pattern of survey findings was aligned, but some variation, incomplete uptake, uncertainty, or limitations in comparability remained.
- **Fully discordant:** Reserved for findings that clearly and consistently contradicted a common direction across the relevant guidelines, based on sufficiently direct survey data and with little ambiguity in interpretation.
- **Broadly discordant:** Used where survey findings indicated a meaningful departure from the prevailing guideline direction, but the departure was not uniform, or interpretation was limited by mixed findings, incomplete clinical context, or limitations in the survey measure.
- **System-level implementation gap:** Used for topics in which guidelines expressed a consistent overarching care objective and the available survey measures were sufficiently direct to assess implementation, despite the absence of a specific quantitative or organisational benchmark. This classification represented an interpretation of the combined guideline and survey findings rather than a directly observed outcome and did not imply a causal explanation or a specific organisational solution.
- **Not assessable:** Used where guideline positions were inconsistent or insufficiently specific, or where the survey data did not directly or adequately capture the relevant aspect of care.

These classifications, assigned by the authors, represented structured qualitative judgements rather than predefined quantitative cut-offs. Where only one survey addressed a topic, an assessment was made only when that survey provided sufficiently direct information, and the absence of complementary data was noted in the interpretation.

3.7 Quality Assurance

To ensure the quality of this report, an internal review was conducted by two internal reviewers (CS) (IZK) and an external review by three independent expert. Reviewers were asked to evaluate the report against the following criteria:

- technical accuracy and reliability of the evidence presented; consideration of current research findings;
- appropriateness and transparency of the methodological approach;
- logical structure and internal consistency;
- adherence to formal standards of scientific writing, including accurate citation practice.

External peer review by independent scientific experts is a core element of the Austrian Institute for Health Technology Assessment (AIHTA) quality assurance framework. Responsibility for the content of this report remains with the AIHTA.

**interne & externe
Begutachtung zur
Qualitätssicherung**

4 Results: Guidelines

4.1 Guideline Synopsis

4.1.1 Included Guidelines

We identified five guidelines that met the specified inclusion criteria for the guideline synopsis: ESHRE [31], Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) [32], National Institute for Health and Care Excellence (NICE) [33], Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF, engl. Working Group of Scientific Medical Societies) [34] and Health Service Executive (HSE) [35]. Four guidelines originate from Europe and one from Australia and were published between 2017 and 2025. Key characteristics of the included guidelines are summarised in Table 4-1.

5 Leitlinien aus Europa & Australien eingeschlossen

4.1.2 Appraisal and Guideline Characteristics

During quality appraisal using the AGREE II instrument, domain scores were calculated across all five included guidelines (Figure 4-1). Overall, the guidelines performed strongly in Domain 1 (Scope and Purpose), with all guidelines scoring between 88.9% and 100%, and in Domain 2 (Stakeholder Involvement), where scores ranged from 75% to 94.4%. Domain 3 (Rigour of Development) showed variability, with scores ranging from 83.3% (NICE) to 97.3% (ESHRE), while AWMF and HSE performed comparatively lower in this domain, achieving less than 50%.

starke Qualität bei Zielsetzung und Stakeholder-Einbindung, Unterschiede bei Methodik

Domain 4 (Clarity of Presentation) was generally well addressed, with most guidelines achieving high scores (approximately 77.8%-100%), indicating that recommendations were clearly structured and easy to identify.

Hohe Klarheit und gute Auffindbarkeit der Empfehlungen

The most notable variation across guidelines was observed in Domain 5 (Applicability) and Domain 6 (Editorial Independence), where scores were overall lower and more heterogeneous. Domain 5 scores ranged from 27.1% (AWMF) to 45.8% (NICE), indicating that applicability, including implementation tools, resource implications, and monitoring criteria, represented a consistent weakness across all included guidelines. Domain 6 (Editorial Independence) showed similar patterns, ranging from 22.9% (RANZCOG) to 91.7% (NICE), with RANZCOG and AWMF performing particularly poorly in this domain.

Schwächen bei Anwendbarkeit und redaktioneller Unabhängigkeit

Overall, NICE demonstrated the most consistent performance across all six domains, with five of six domains scoring above 90%. It was still classified as moderate quality according to the predefined thresholds. RANZCOG, along with ESHRE and HSE, also achieved moderate quality ratings, with strong performance in scope, stakeholder involvement, and clarity, but lower scores in applicability and editorial independence, domains that were generally weaker across most guidelines. AWMF showed the weakest overall performance and was classified as low quality, with several domains scoring below 50%. No guideline fulfilled the criteria for high quality across all six AGREEII domains.

keine Leitlinie erreicht hohe Qualität nach AGREE II

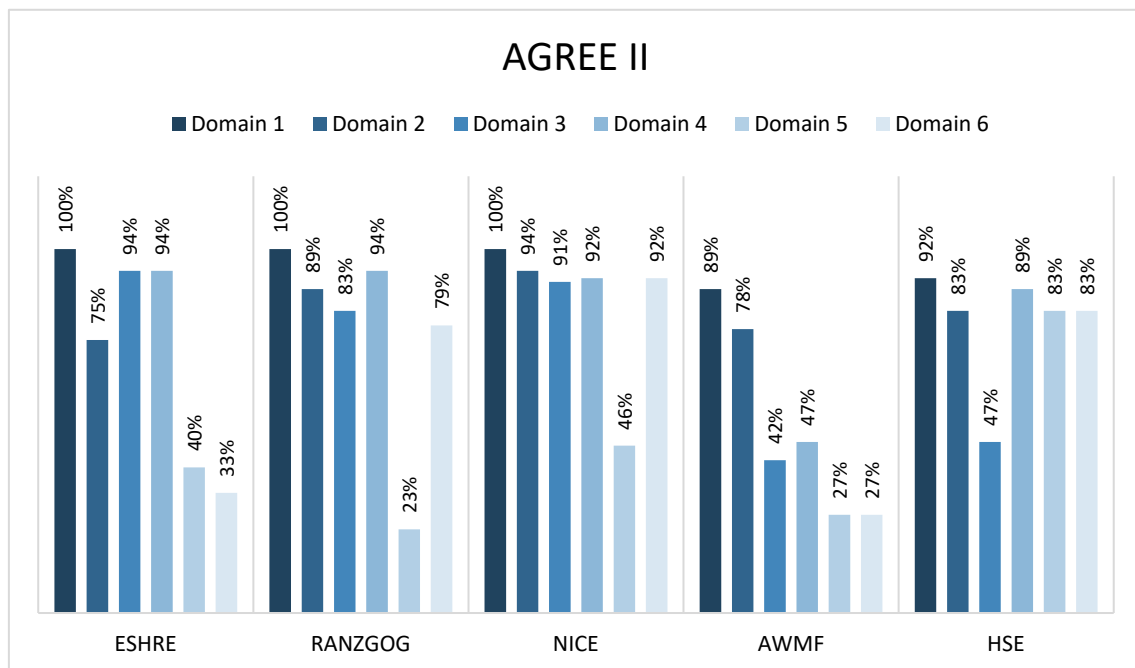


Figure 4-1: Quality appraisal

All guidelines address the diagnosis and management of endometriosis across the full care continuum, from primary care to specialist and tertiary services. The target population consistently includes women and people with suspected or confirmed endometriosis, encompassing adolescents, postmenopausal individuals, and, in several guidelines, transgender, non-binary, and gender-diverse individuals; the RANZCOG guideline gives particular attention to First Nations people and rural/remote populations.

The evidence base draws primarily on systematic reviews and meta-analyses, supplemented by RCTs, observational studies, and expert consensus where higher-level evidence was unavailable. The HSE guideline was adapted from ESHRE 2022, NICE NG73, and RANZCOG 2021. Funding arrangements varied across guidelines, with development group members generally contributing on a voluntary basis (see Table 4-1).

**Leitlinien umfassen
verschiedene
Versorgungsebenen &
Patient:innengruppen**

**Unterschiede
in Evidenzbasis &
Leitlinienentwicklung**

Table 4-1: Characteristics of included guidelines

Institute	Year	Country/Region	Title	Target Population	Evidence Base	Funding Source
ESHRE [31]	2022	multinational (Europe)	Endometriosis Guideline of European Society of Human Reproduction and Embryology	Women with suspected or confirmed endometriosis (including adolescents, postmenopausal women, and those with extrapelvic or asymptomatic disease)	SRs/meta-analyses (primary); RCTs and observational studies (where SRs are unavailable)	Meeting/literature/publication costs covered; GDG members unpaid (travel reimbursement only)
RANZCOG [32]	2025	Australia (with New Zealand representation)	Australian Living Evidence Guideline: Endometriosis ¹	People of all ages (including adolescents from age 10) with suspected or confirmed endometriosis or adenomyosis; explicitly includes cisgender women, transgender, non-binary and gender-diverse people, intersex people; special consideration of First Nations people, rural/remote populations, people with disabilities, and people from culturally and linguistically diverse backgrounds	Adapted + SR ²	Australian Government (Dept. of Health & Aged Care); administered via RANZCOG (National Action Plan for Endometriosis/Medical Research Future Fund)
NICE [33]	2017 updated 2024	United Kingdom	Endometriosis: diagnosis and management	Women and people with suspected or confirmed endometriosis, including trans men, non-binary people, and adolescents (aged 17 and under)	SRs (primary); expert opinion (where evidence unavailable)	NICE (publicly funded); BMJ summary authors unfunded
AWMF [34]	2025	Germany, Austria, Switzerland (DACH region + Czech Republic)	Diagnostik und Therapie der Endometriose	Women/persons with diagnosed or suspected endometriosis, including adolescents; all age groups from pre-menarche to postmenopause	SRs, meta-analyses, RCTs (primary); expert consensus (where evidence is insufficient)	DGGG Guideline Programme (€7,500 for literature searches, editorial revision, proofreading, consensus conferences); coordinators/mandate holders voluntary
HSE [35]	2025	Ireland	National Clinical Practical Guideline	Women undergoing assessment and management of endometriosis across primary care, general and specialist gynaecology, and tertiary services in Ireland	SRs, RCTs, observational studies (primary); adapted from ESHRE 2022, NICE NG73 2017, RANZCOG 2021; supplemented by Medline, EMBASE, Cochrane (to June 2023)	HSE/National Women and Infants Health Programme; no external funding reported

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); BMJ ... British Medical Journal; DACH ... Deutschland, Österreich, Schweiz (Germany, Austria, Switzerland); Dept ... Department; DGGG ... Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (engl. German Society for Gynaecology and Obstetrics); EMBASE ... Excerpta Medica Database; ESHRE ... European Society of Human Reproduction and Embryology; GDG ... Guideline Development Group; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; NIHR ... National Institute for Health and Care Research; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; RCT ... Randomised Controlled Trial; SR ... Systematic Review

Notes:

¹ RANZCOG is the only guideline in this review developed as a living document, subject to continuous updates as new evidence emerges.

² "Adapted" indicates that the guideline was based on existing guidelines rather than developed de novo, supplemented by additional systematic review where required.

All five guidelines report a described evidence search, conflict of interest (COI) management, and an editorial independence statement. Four guidelines (ESHRE, RANZCOG, NICE, HSE) apply GRADE or a partial GRADE approach for rating evidence quality, while the AWMF guideline does not use GRADE. External review and update procedures are reported across all five guidelines.

Regarding update models, four guidelines follow a periodic update cycle, with validity periods ranging from 2026 (ESHRE) to 2030 (AWMF). The RANZCOG guideline is maintained as a living guideline with no fixed expiry date, reflecting its continuous update model. NICE does not specify a fixed validity period but conducts regular post-publication reviews to determine the need for an update (see Table 4-2).

methodische
Qualitätsmerkmale
der Leitlinien

Update-Modelle &
Gültigkeitszeiträume
der Leitlinien

Table 4-2: Methodological characteristics of included guidelines

Guideline	Update Model	Validity	Evidence Search Described	GRADE	External Review Reported	Update Procedure Reported	COI Reported	Editorial Independence Statement
ESHRE [31]	Periodic	2026	✓	Partial	✓	✓	✓	✓
RANZCOG [32]	Living	No fixed expiry stated	✓	✓	✓	✓	✓	✓
NICE [33]	Periodic	Not stated; regular post-publication review by NICE	✓	✓	✓	✓	✓	✓
AWMF [34]	Periodic	March 2030	✓	X	X	✓	✓	✓
HSE [35]	Periodic	March 2028	✓	Partial	✓	✓	✓	✓

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); COI ... Conflict of Interest; ESHRE ... European Society of Human Reproduction and Embryology; GRADE ... Grading of Recommendations Assessment, Development and Evaluation; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

4.2 Guideline Recommendations

The results presented in this section are based on the five clinical guidelines included in this review. As the source guidelines differ in scope, wording, level of detail and evidence grading systems, direct comparison of recommendation strength and evidence quality was limited (please refer to Methods section for details) ESHRE and RANZCOG use GRADE-based approaches, with recommendation strength and certainty of evidence reported separately (certainty ranging from ⊕○○○ = very low to ⊕⊕⊕⊕ = high); NICE formulates recommendations based on the committee’s consensus of the evidence certainty, benefits and harms, and contextual factors. AWMF is an S2k consensus-based guideline; recommendations are developed and adopted through a structured consensus process, but no schematic evidence grades or formal recommendation grades are assigned (+ to +++). HSE provides graded recommendations alongside Best Practice statements (1A-1C, Best Practice). Details on Guideline specific recommendation strength and evidence certainty are provided in the Appendix.

Evidence Grading
Across Guidelines;
methodische
Unterschiede begrenzen
Vergleichbarkeit der
Empfehlungen

4.2.1 Diagnostic Workup

Signs and Symptoms

Core Symptoms

All five guidelines recommend considering endometriosis in individuals presenting with one or more of the following characteristic symptoms:

- dysmenorrhea (painful periods)
- deep dyspareunia (pain during or after sexual intercourse)
- chronic pelvic pain
- cyclical gastrointestinal symptoms, particularly dyschezia (painful defaecation)
- cyclical urinary symptoms, such as dysuria and haematuria
- infertility.

In all five guidelines, these symptoms serve as the primary trigger for further diagnostic evaluations, although the underlying recommendations are largely consensus-based and generally supported by low or very low certainty evidence.

Beyond this shared core, ESHRE and RANZCOG broaden the profile to include less common and extrapelvic features, such as cyclical respiratory symptoms and bowel disturbances, while NICE states that infertility in association with one or more of these symptoms should prompt consideration of endometriosis.

Symptom Documentation and History-Taking

Three guidelines (ESHRE, RANZCOG, NICE) recommend that clinicians advise patients to keep a symptom or pain diary to support diagnosis and ongoing management. AWMF recommends a structured pain history for all patients with endometriosis and/or chronic pelvic pain. They also emphasise a broader psychosomatic assessment, including evaluation for sexual dysfunction and screening for anxiety and depression.

Both NICE and RANZCOG recommend enquiring about a family history of endometriosis in first-degree relatives, with RANZCOG additionally recommending inclusion of history of autoimmune disease, noting an association with endometriosis risk.

Recommendations regarding history taking and symptom assessment are largely based on expert consensus, reflecting the limited availability of high-quality evidence. The recommendations are driven by the clinical importance of early recognition and the potential of delayed diagnosis.

Clinical Examination

All five guidelines include clinical examination as part of the diagnostic work-up, although the level of detail varies. Most explicitly refer to abdominal and/or pelvic examination to identify findings such as tenderness, nodularity, reduced organ mobility or masses, and emphasise that normal findings do not exclude endometriosis. Recommendations are largely based on consensus or good-practice guidance rather than higher-certainty evidence.

**Leitsymptome für
weitere Abklärung**

**Dysmenorrhoe,
Dyspareunie,
Beckenschmerzen,
zyklische Darm- oder
Harnwegssymptome &
Infertilität**

**3 Leitlinien
empfehlen strukturierte
Symptomerhebung**

**Familienanamnese &
Autoimmunerkrankungen
in 2 Leitlinien adressiert**

**klinische Untersuchung
leitlinienübergreifend
empfohlen**

Diagnostic Imaging

Transvaginal Ultrasound as First-Line Investigation

Most guidelines (RANZCOG, NICE, AWMF, HSE) recommend TVUS as the first-line imaging modality, while ESHRE recommends imaging in general (TVUS or MRI), without a clear preference. RANZCOG and NICE advise offering TVUS regardless of examination findings, with NICE further stating that imaging may be performed alongside empirical treatment. Where graded, recommendations for TVUS are generally strong, although the certainty of supporting evidence varies from low to moderate.

Across guidelines, utilisation of imaging is recommended to identify endometriomas, detect deep disease, exclude alternative diagnoses, and guide management. All emphasise that a negative ultrasound does not exclude endometriosis, particularly superficial disease, which remains poorly detected by current imaging modalities.

ESHRE, NICE, and HSE suggest that referral and further assessment remain appropriate even when imaging results are normal.

Where TVUS is declined or not appropriate, RANZCOG, NICE, and HSE suggest transabdominal ultrasound (TAUS) as an alternative. RANZCOG further specifies that pelvic MRI may be used where pelvic ultrasound is not suitable.

MRI

MRI is consistently positioned as a second-line diagnostic tool across all guidelines, particularly where DIE is suspected. ESHRE recommends MRI additionally as an option for the diagnostic workup, noting that a negative result does not exclude disease. RANZCOG and NICE recommend MRI when deep disease is suspected, including for assessment of disease extent and preoperative planning. AWMF designates MRI as second-line when TVUS is inconclusive. HSE explicitly recommends against MRI as a routine first-line investigation and instead reserves its use for suspected deep disease involving the bowel, bladder, or ureter. Overall, the direction of guidance is consistent, although the recommendation strength and certainty of evidence vary substantially.

RANZCOG, NICE, and AWMF specify that specialist-conducted ultrasound and pelvic MRI should be performed and interpreted by a healthcare professional with expertise in gynaecological imaging.

CT and PET-CT

CT and PET-CT play no established role in routine diagnostic assessment. RANZCOG advises against CT as a primary investigative modality for endometriosis, and HSE issues a weak recommendation against CT or PET-CT for diagnosis. ESHRE, NICE and AWMF do not address these modalities in this context.

Laparoscopy

All five guidelines address laparoscopy within the diagnostic pathway, generally presenting it as an option when non-invasive investigations are inconclusive or when imaging findings are normal or non-diagnostic despite ongoing symptoms. ESHRE, RANZCOG, NICE and HSE all support considering laparoscopy in such situations; RANZCOG further specifies that this should gen-

TVUS
leitlinienübergreifend
als erste bildgebende
Untersuchung empfohlen

negativer Befund schließt
Endometriose nicht aus

Überweisung und weitere
Abklärung auch bei
unauffälliger Bildgebung

MRT leitlinienübergreifend
als Zweitlinien-Diagnostik

v. a. bei Verdacht auf
tiefe Endometriose

z. T. Bildgebung durch
spezialisierte Fachkräfte
empfohlen

CT/PET-CT:
nur vereinzelt adressiert,
nicht empfohlen

Laparoskopie bei
unklarer Diagnostik als
leitlinienübergreifende
Option

erally follow an initial trial of treatment. The direction of guidance is broadly consistent, although the basis and strength of recommendations vary, ranging from good practice statements or committee consensus to strong recommendations supported by moderate-quality evidence.

RANZCOG and NICE provide more detailed recommendations on laparoscopic assessment and documentation. RANZCOG recommends comprehensive documentation of findings, including lesion site and appearance, with photographic documentation and biopsy where possible. NICE emphasises appropriate laparoscopic training, systematic inspection of the entire pelvis, and recording of both normal and abnormal findings, including intraoperative imaging where appropriate. Across guidelines, biopsy for histological confirmation is recommended where possible, while acknowledging that negative histology does not entirely exclude endometriosis.

Dokumentation & histologische Sicherung bei Laparoskopie

Biomarkers and Serum CA-125

All five guidelines advise against using biomarkers to diagnose endometriosis. Serum CA-125, in particular, is not considered sufficiently reliable for diagnostic use, as elevated levels (≥ 35 IU/mL) may be compatible with endometriosis, but normal levels do not exclude the disease. The direction of guidance is highly consistent and mostly strong across guidelines, and supporting evidence is generally moderate to high, with lower certainty only reported by NICE.

leitlinienübergreifende Empfehlung gegen CA-125 zur Diagnose

Classification Systems

Only AWMF provides detailed guidance on formal classification, recommending the use of the #Enzian classification (2021) to describe imaging and intraoperative findings. The rASRM score and AAGL classification may additionally be used intraoperatively, although they note concerns regarding reproducibility and limited ability to capture pain, infertility, or predict disease progression.

**AWMF:
#Enzian, rASRM & AAGL
Klassifikation zu
intraoperativer
Dokumentation**

NICE and RANZCOG do not emphasise formal classification, instead recommending detailed documentation of disease location and appearance, with NICE advising that treatment decisions be guided by symptoms and patient preferences rather than disease stage.

Additional Diagnostic Considerations

Renal and Urological Assessment

AWMF is the only guideline to provide specific recommendations on urological assessment. It recommends bilateral renal ultrasound in suspected or confirmed deep infiltrating, ovarian, or bowel endometriosis due to the risk of urinary tract involvement and clinically silent hydronephrosis. They also advise appropriate differential diagnostic evaluation in cases of haematochezia.

**AWMF:
Nierensonografie bei
tiefer Endometriose**

Ovarian Reserve

AWMF is the only guideline to address ovarian reserve as part of the pre-treatment workup. It recommends measuring anti-Müllerian hormone (AMH) before deciding on a treatment strategy for ovarian endometriosis.

**AWMF:
AMH-Bestimmung bei
ovarieller Endometriose**

Psychosocial Assessment and Sexual Dysfunction

AWMF and ESHRE address psychosocial aspects of care. AWMF highlights the importance of assessing sexual dysfunction, anxiety and depression in patients with endometriosis. ESHRE suggests psychological support, particularly for patients with deep and ovarian endometriosis, while NICE and HSE more broadly acknowledge patients psychosexual and emotional support needs within care pathways. RANZCOG does not address psychosocial assessment in the diagnostic section reviewed.

**AWMF & ESHRE:
adressieren psychosoziale
Aspekte**

For further detail on the level of evidence and strength of recommendation for each diagnostic work-up, please refer to Table 4-3.

Table 4-3: Diagnostic work-up: Key recommendations strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Perform pelvic and/or abdominal examination	Strong/ ⊕○○○	Good Practice Statement	Strong/ Consensus only	—	Strong/ 1C
TVUS as first line imaging despite normal clinical examination*	Strong/ ⊕⊕○○	Strong/ ⊕⊕⊕○	Strong/ moderate	+++	Strong/ 1A/B
Negative imaging does not exclude endometriosis	Strong/ ⊕⊕○○	Good Practice Statement	Strong/ moderate	—	Strong/ 1B
MRI as second-line/for deep disease	Strong/ ⊕⊕○○	Good Practice Statement	Weak/ very low–moderate	+++	Strong/ 1B
Do not use biomarkers/serum CA-125	Strong/ ⊕⊕⊕○	Conditional/ ⊕⊕⊕○	Strong/ very low	+++	Strong/ 1A
Consider laparoscopy if imaging negative/empirical treatment fails	GPP/n/a	Strong/ ⊕⊕⊕○	Weak/ committee consensus	—	Strong/ 1B
Psychosocial assessment/sexual dysfunction screening	Weak/ ⊕○○○	—	—	+++ (statement)	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); CA-125 ... Cancer Antigen 125; CT ... computed tomography; ESHRE ... European Society of Human Reproduction and Embryology; GPP ... Good Practice Point; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; PET-CT ... positron emission tomography/computed tomography scan; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; TVUS ... Trans Vaginal Ultrasound

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.2 Treatment of Endometriosis-Associated Pain

Analgetics

NSAIDs and Simple Analgesics

All five guidelines recommend analgesics for endometriosis-associated pain, consistently noting weak recommendations based on low- to very low-quality evidence. ESHRE suggests NSAIDs or other analgesics alone or in combination with other treatments. RANZCOG and NICE recommend a short trial of NSAIDs with or without paracetamol as a first step, with further options and gynaecology referral if relief is inadequate. AWMF recommends NSAIDs for nociceptive pain relief and HSE supports offering paracetamol, NSAIDs, and neuromodulators to reduce pain.

**Analgetika
konsistent empfohlen,
Evidenz schwach**

Opioids and Extended Analgesic Options

AWMF provides the most detailed guidance, listing tricyclic antidepressants, cannabis-based medicines, gabapentinoids, metamizole, paracetamol, SNRIs, and opioids as options depending on the underlying pain mechanism, and recommending regular multidisciplinary review of long-term analgesic medication, involving pain medicine and psychotherapy specialists. ESHRE and NICE do not provide specific recommendations on opioids.

AWMF:
differenzierte
Schmerztherapie &
interdisziplinäre
Verlaufskontrolle

Neuromodulators

RANZCOG suggests discussing the potential benefits and harms of neuromodulators, noting limited evidence specific to endometriosis. NICE refers to its separate neuropathic pain guideline without providing specific guidance here. AWMF includes gabapentinoids and SNRIs for chronic pain depending on the pain mechanism, while HSE includes neuromodulators within its broader analgesic recommendation.

Neuromodulatoren
bei chronischem Schmerz
erwogen

Hormonal Treatment

General Principles

All guidelines recommend hormonal therapy as a treatment option for endometriosis-associated pain. Choice of treatment should be individualised, considering patient preferences, side effects, efficacy, costs, availability, and reproductive intentions.

hormonelle Therapie
leitlinienübergreifend
empfohlen

First-Line Hormonal Treatments

Combined Hormonal Contraceptives

Combined hormonal contraceptives (CHCs) are recommended by ESHRE for endometriosis-associated pain, including dyspareunia, dysmenorrhoea and non-menstrual pain; continuous use may be offered for dysmenorrhoea. RANZCOG, NICE and HSE position CHCs as first-line treatment, whereas AWMF considers them second-line.

kombinierte Kontrazeptiva
meist als Erstlinienoption
empfohlen

All guidelines recommend progestogens as a first-line option, although the formulations and level of detail vary. ESHRE specifically includes the levonorgestrel-releasing intrauterine system and etonogestrel implant, while RANZCOG covers oral, injectable, implant and intrauterine options within shared decision-making. NICE also recommends progestogens as a hormonal treatment option. AWMF recommends a suitable progestogen, such as dienogest, as first-line pharmacological treatment after surgically confirmed endometriosis, and HSE positions progestogens alongside CHCs as first-line treatment.

Gestagene einheitlich
als Erstlinienoption
empfohlen

Overall, concordance is highest for progestogens, which are consistently positioned as first-line treatment. CHCs are also generally first-line, except in AWMF, where they are second-line after surgery. Recommendations are generally strong, although evidence certainty varies across grading systems.

Second-Line Treatments

GnRH Agonists/Antagonists

GnRH agonists and/or antagonists are generally recommended as second-line options for endometriosis-associated pain when first-line hormonal treatment is ineffective, not tolerated, or contraindicated. NICE primarily links their use to specialist care and short-term preoperative treatment in selected DIE cases. Add-back therapy is consistently emphasised to reduce hypoestrogenic symptoms and bone loss. The strength of recommendations and certainty of evidence vary across guidelines: recommendations for GnRH agonists are generally strong despite low to moderate certainty of evidence, whereas recommendations for GnRH antagonists are more heterogeneous, ranging from weak or conditional recommendations to strong or consensus-based recommendations. AWMF is the notable exception, positioning oral GnRH antagonists with add-back therapy more prominently, including as a first-line pharmacological option after confirmed surgical diagnosis.

**GnRH-Analoga meist
als Zweitlinientherapie**

**Fokus auf
Add-back-Therapie**

**GnRH-Antagonisten
uneinheitlich eingeordnet**

Other Treatment

Aromatase Inhibitors and SERMs

Aromatase inhibitors are addressed inconsistently across guidelines. ESHRE recommends their use for endometriosis-associated pain that is refractory to other medical or surgical treatments, usually in combination with other hormonal therapies. In contrast, RANZCOG does not recommend aromatase inhibitors or SERMs because of very limited supporting evidence, while NICE, AWMF, and HSE do not provide specific recommendations in the reviewed sections.

**Aromatasehemmer nur
vereinzelt empfohlen**

Long-Term Hormonal Therapy and Perioperative Hormonal Treatment

Postoperative or long-term hormonal therapy is broadly supported across guidelines for patients not actively trying to conceive, particularly for symptom control and reduction of recurrence risk. Where specified, response to first-line hormonal treatment should be reviewed after an initial trial period and adapted if ineffective or not tolerated.

**langfristig
Hormontherapie
bei nicht bestehendem
Kinderwunsch empfohlen**

Regarding preoperative hormonal treatment, ESHRE and NICE both address this area but reach different conclusions: ESHRE recommends against its routine use, whereas NICE recommends considering three months of GnRH agonist treatment before surgery for DIE involving the bowel, bladder or ureter.

**uneinheitliche
Empfehlungen
zur präoperativen
Hormontherapie**

For patients with a history of endometriosis requiring menopausal hormone therapy, HSE recommends a continuous oestrogen-progestogen regimen in general.

Surgical Treatment

General Principles

Across all guidelines, surgery is consistently presented as one treatment option for endometriosis-associated pain, and guidelines addressing surgical route generally favour laparoscopy over laparotomy. ESHRE, RANZCOG, and NICE specify that patients should be informed of the potential risks, benefits, and long-term effects on quality of life before surgery, including the possible need for further surgery involving the bowel, bladder, or ureter.

**operative Therapie
leitlinienübergreifend
als Option mit
Laparoskopiepräferenz**

RANZCOG additionally notes that, with the exception of endometrioma, surgery may or may not improve symptoms, and that the benefits and harms of diagnostic versus therapeutic laparoscopy should be discussed prior to the procedure in cases of suspected endometriosis without a confirmed diagnosis. Overall, the direction of guidance is concordant and generally strongly supportive, although the grading basis varies across guidelines, ranging from good practice statements to strong recommendations supported by higher-level evidence.

Aufklärung zu Nutzen, Risiken & möglichem OP-Erfolg empfohlen

Peritoneal and Superficial Endometriosis

ESHRE and HSE suggest considering excision over ablation, although these are weak recommendations, and the certainty of supporting evidence varies. In contrast, RANZCOG and AWMF consider excision and ablation to be equivalent in efficacy. NICE recommends considering the treatment of suitable peritoneal lesions during diagnostic laparoscopy without specifying a technique. AWMF additionally recommends that complete primary treatment should be attempted when symptomatic peritoneal endometriosis is identified and discourages planned second-look laparoscopy.

peritoneale Läsionen: Vorteil von Exzision vs. Ablation unklar

Ovarian Endometrioma

For ovarian endometrioma, most guidelines favour cystectomy over drainage and coagulation because of lower recurrence rates and reduced endometriosis-associated pain. ESHRE and HSE additionally note that CO₂ laser vaporisation may be considered as an alternative to cystectomy, with ESHRE reporting similar long-term recurrence rates, but potentially lower early recurrence after cystectomy. Overall, the direction of guidance is broadly concordant, with strong recommendations from ESHRE, RANZCOG, and HSE, weaker guidance in NICE, and variation in the certainty of supporting evidence. The choice should consider fertility desire, ovarian reserve, and previous ovarian surgery.

Ovarialendometriom: Zystektomie leitlinienübergreifend bevorzugt; individuelle Faktoren entscheidend

Preservation of ovarian function is a central concern, with ESHRE recommending caution to minimise ovarian damage. AWMF states that all surgical approaches reduce ovarian reserve and that endometrioma removal carries an increased risk of premature ovarian insufficiency. HSE similarly recommends caution to minimise ovarian damage and further notes that deeply infiltrating endometriosis is commonly detected during endometrioma surgery and should be anticipated.

Ovarialreserve schützen

Deep Infiltrating Endometriosis

Overall, guidance supports specialist-led surgery for symptomatic DIE, although the strength of recommendations and the certainty of the evidence vary across guidelines.

tiefe Endometriose: operative Versorgung in spezialisierten Zentren empfohlen

ESHRE and HSE state that surgical removal of DIE may reduce pain and improve quality of life, while ESHRE also suggests referral to a centre of expertise. RANZCOG recommends specialist referral for DIE involving the pelvic side wall, bowel or bladder.

AWMF recommends that complete resection should be the goal in symptomatic patients when the expected benefits outweigh the surgical risks of organ dysfunction, and that complete resection should also be aimed for in symptomatic rectovaginal and vaginal endometriosis when medical therapy provides insufficient relief.

AWMF: vollständige Resektion unter Nutzen-Risiko-Abwägung

Hysterectomy/Oophorectomy

All five guidelines address hysterectomy, with or without oophorectomy, as an option for patients who do not wish to conceive and whose symptoms persist despite conservative treatment. The direction of guidance is broadly consistent, but recommendation strength and certainty of evidence vary, with several statements based on low or very low certainty evidence or good practice guidance. ESHRE, RANZCOG, NICE, and HSE emphasise counselling on potential benefits and risks, including that hysterectomy may not fully resolve symptoms and that bilateral oophorectomy may lead to early menopause and possible need for menopausal hormone therapy. Where specified, total rather than subtotal hysterectomy is preferred, and visible endometriotic lesions should be exercised at the time of hysterectomy. NICE and RANZCOG additionally state that hysterectomy combined with endometriosis treatment should be performed laparoscopically unless contraindicated.

**Hysterektomie ±
Oophorektomie
leitlinienübergreifend
als Option bei
therapieresistenten
Beschwerden**

**Aufklärung zu
Symptompersistenz &
früher Menopause
empfohlen**

Complementary therapeutic interventions

Complementary therapeutic interventions are addressed unevenly across guidelines, with specific guidance identified only for selected interventions. Overall, recommendations are largely based on consensus guidance or very low-certainty evidence. As formal evidence grading was rarely available or applicable across these topics, the quality of evidence is not reported separately in the following subsections. ESHRE and HSE state that no specific complementary interventions can be recommended to reduce pain or improve quality of life, but that these strategies may be discussed to support wellbeing.

**nicht-medikamentöse
Verfahren:
Evidenz meist unsicher**

Physiotherapy

RANZCOG suggests pelvic physiotherapy for pelvic pain and pain during sex. AWMF recommends physiotherapy tailored to individual symptoms and states that progressive muscle relaxation and lower abdominal self-massage may be considered for menstrual pain.

**RANZCOG & AWMF:
symptomorientierte
Physiotherapie als Option**

Psychological Interventions

RANZCOG suggests mindfulness classes, psychological interventions, and counselling for small improvements in pelvic pain and quality of life. AWMF recommends psychotherapy, particularly CBT and mindfulness-based interventions, for high symptom burden, its integration into multimodal treatment for chronic pain, and interdisciplinary multimodal pain therapy when a chronic pain disorder is present.

**psychologische
Interventionen bei hoher
Symptomlast erwägen**

Acupuncture

RANZCOG suggests acupuncture for short-term pain and quality of life improvements, noting limited evidence for other CAM therapies. AWMF suggests approximately eight sessions as an adjunct for pelvic pain/menstrual symptoms. NICE does not address acupuncture specifically but recommends against the use of Chinese Medicine for treating endometriosis due to lack of supporting evidence.

**NICE:
Chinesische Medizin
mangels Evidenz
nicht empfohlen**

Diets and Nutrition

RANZCOG suggests discussing a FODMAP diet and supplements (fish oil, vitamin D), noting that the evidence is limited. AWMF recommends a healthy diet rich in vitamins and fibre, advising against specific diets without a clear indication.

**Ernährungsempfehlungen
nur vereinzelt & unsicher**

TENS and Electrostimulation

AWMF states TENS and vaginal electrostimulation may be considered for chronic pain.

**weitere Zusatztherapien
vereinzelt genannt,
Evidenz begrenzt**

Osteopathy, Exercise, and Other Physical Approaches

AWMF states osteopathic treatment may be considered and recommends regular physical exercise, aerobic training, yoga, or stretching, for menstrual pain relief.

Medicinal Cannabis

RANZCOG recommends openly discussing medicinal and non-prescribed cannabis given its common use, but makes no specific recommendation due to limited evidence, and notes relevant prescribing regulations. AWMF includes cannabis-based medicines in its analgesic options for chronic pain by mechanism.

Sexual Dysfunction

AWMF recommends offering psychosexual counselling or therapy when sexual dysfunction is present.

For further detail on the level of evidence and strength of recommendation for each treatment, please refer to Table 4-4.

Table 4-4: Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Analgesics/NSAIDs (alone or in combination with other treatments)	Weak/ ⊕○○○	Conditional/ ⊕○○○ (Very low)	Strong/Very low, (expert consensus)	+++ (recommendation)	Weak/ 2B
Combined hormonal contraceptives (first-line)	Strong/ ⊕⊕○○	Conditional/ ⊕⊕○○	Strong/Moderate	Second-line (after surgery)	Strong/ 1A
Progestogens (first-line)	Strong/ ⊕⊕○○	Conditional/ ⊕⊕○○	Strong/Moderate	+++ (recommendation)	Strong/ 1A
GnRH agonists (second-line)	Strong/ ⊕⊕○○	Conditional/ ⊕⊕⊕○	—	++ (recommendation)	Best practice
GnRH antagonists	Weak/ ⊕⊕⊕○	Conditional/ ⊕⊕○○	—	+++ (recommendation)	Best practice
Add-back therapy with GnRH analogues	GPP	Strong/ ⊕⊕⊕○	—	+++ (recommendation)	Best practice
Aromatase inhibitors (refractory pain)	Strong/ ⊕⊕⊕○	Not recommended/ ⊕⊕○○	—	—	—
Surgery as one of the options for pain	Strong/ ⊕⊕○○	Good Practice Statement	Strong/low	+++ (recommendation)	Strong/ 1A
Laparoscopic approach (not laparotomy)	—	Good Practice Statement	Strong/low	+++ (recommendation)	—
Cystectomy preferred over drainage and coagulation for endometrioma	Strong/ ⊕⊕○○	Strong/ ⊕⊕⊕○	Weak/low	+++ (statement)	1B
Minimise ovarian damage during endometrioma surgery	Strong/ ⊕○○○	Good Practice Statement	—	+++ (statement)	Best practice
Surgery for DIE: aim for complete resection	Weak/ ⊕⊕○○	Good Practice Statement	—	+++ (recommendation)	Strong/ 1B
Total hysterectomy + excision of all visible lesions; perform laparoscopically	GPP	Good Practice Statement	Strong/low	+++ (recommendation) (lesion excision)	Best practice (total hyst.)
Physical therapies: pelvic physiotherapy, exercise osteopathy, TENS/electrostimulation,	—	Conditional/ ⊕⊕○○ (physiotherapy only)	—	+++ (physiotherapy) ++ (others)	—

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Acupuncture limited evidence for other CAM	—	Conditional/ ⊕⊕○○	—	++ (recommendation)	—
Healthy diets and nutritional supplements	—	Conditional/ ⊕○○○	—	+++ (recommendation)	—
Psychological interventions counselling; multimodal pain therapy for chronic pain; psychosexual counselling for sexual dysfunction	—	Conditional/ ⊕⊕○○ (psych. interventions)	—	+++ / ++ (psych.) +++ (multimodal + sexual dysfunction)	—
Chinese medicine/herbal supplements: not supported by evidence	—	—	Strong (no evidence)	—	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); CAM ... Complementary and alternative medicine; DIE ... deep infiltrating endometriosis; ESHRE ... European Society of Human Reproduction and Embryology; GnRH ... Gonadotropin-releasing hormone; GPP ... Good Practice Point; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; NSAIDs ... Non-steroidal anti-inflammatory drugs; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; TENS ... Transcutaneous electrical nerve stimulation

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.3 Treatment of Endometriosis-Associated Infertility

Medical Treatment

Overall, treatment recommendations are broadly aligned in direction, but differ substantially in scope, recommendation strength and underlying certainty of evidence across guidelines.

Hormonal Suppression:

ESHRE, RANZCOG, and HSE recommend against hormonal suppression to improve fertility in individuals trying to conceive. Whilst they are concordant in direction, both the certainty of evidence and the strength of recommendation vary, ranging from low to high and from conditional to strong, respectively.

**Hormonsuppression zur
Fertilitätsverbesserung
nicht empfohlen**

In addition, two guidelines address postoperative hormonal treatment in those not immediately seeking pregnancy. ESHRE makes a weak recommendation, based on low evidence quality, that hormone therapy may be offered after surgery, as it improves pain outcomes without negatively impacting fertility. In contrast, RANZCOG issues a strong recommendation, based on moderate evidence quality to the same effect, noting reductions in pain and recurrence.

**postoperative
Hormontherapie
bei aufgeschobenem
Kinderwunsch vereinzelt
unterstützt**

Fertility Counselling, Preservation, and Reproductive Medicine

AWMF provides the most explicit guidance on fertility counselling and preservation, recommending consideration of ovarian function and age in treatment decisions. It advises reproductive counselling, including discussion of potentially reduced fertility, the effect of age, and oocyte/embryo cryopreservation, with fertility preservation offered based on individual benefit-risk assessment. Other guidelines address fertility-related factors mainly in the context of treatment planning or surgical decision-making rather than as separate recommendations on fertility preservation.

**AWMF:
Fertilitätsberatung &
-erhalt detailliert adressiert**

Surgical Treatments

General Principles

ESHRE, RANZCOG, and HSE emphasise individualised fertility-related surgical decision-making, considering age, ovarian reserve, infertility duration, pain symptoms, previous surgery, patient preferences, and other infertility factors. ESHRE additionally refers to the Endometriosis Fertility Index, while RANZCOG highlights multidisciplinary involvement, including fertility expertise. NICE does not provide an equivalent overarching statement in this context, but addresses fertility wishes, ovarian reserve, and fertility-related risks within specific surgical recommendations. AWMF addresses fertility counseling and preservation separately, as outlined above. These recommendations are consensus- or best-practice-based rather than supported by graded evidence.

**OP-Entscheidung bei
Kinderwunsch individuell
abwägen**

Peritoneal Endometriosis

ESHRE, RANZCOG, NICE and HSE support operative laparoscopy with excision or ablation, with or without adhesiolysis, for stage I/II disease, as it may improve ongoing or spontaneous pregnancy rates. RANZCOG additionally suggests considering tubal patency testing at the same time. AWMF provides no specific recommendation. Overall, while guidelines are concordant in direction, the certainty of evidence and strength of recommendation vary, ranging from very low to moderate certainty and from conditional/weak to strong recommendations.

**Stadium I/II:
operative Laparoskopie
zur Fertilität erwägen**

Ovarian Endometrioma

Guidelines addressing endometrioma-related infertility generally support an individualised surgical approach, but recommendations are heterogeneous in strength, scope, emphasis, and certainty of evidence, ranging from weak to strong recommendations and from very low to high-certainty evidence where reported. ESHRE gives a weak recommendation that operative laparoscopy may be considered to increase the chance of natural pregnancy, although comparative data is lacking. NICE recommends laparoscopic cystectomy or drainage and ablation, noting that both may improve spontaneous pregnancy rates and that ablation may better preserve ovarian reserve. AWMF mainly highlights ovarian reserve assessment and fertility-preserving counselling before surgery. HSE emphasises individualised decision-making based on ovarian reserve, previous surgery, symptoms, other fertility investigations, and planned fertility treatment, and advises against routine surgery before ART unless clinically indicated.

**Endometriom & Infertilität:
individualisierte
chirurgische
Entscheidungsfindung**

Deep Infiltrating Endometriosis

For patients with DIE who wish to conceive, ESHRE, RANZCOG, NICE, and HSE consistently recommend discussing the benefits and risks of laparoscopic surgery with patients, while noting the absence of clear evidence for improved fertility outcomes. NICE specifies that discussion should cover the possible impact of DIE on pregnancy outcomes, whether surgery may alter the chance of future pregnancy, the potential impact of surgical complications on fertility, and available alternatives. HSE recommends operative laparoscopy as an option for symptomatic patients guided by pain symptoms and patient preferences. AWMF does not provide a specific recommendation on this topic. Overall, the recommendations are consistent in emphasising shared decision-making rather than fertility benefit, with low to moderate evidence certainty, where reported and recommendation strength ranging from conditional to strong.

**tiefe Endometriose:
OP-Nutzen für Fertilität
unklar**

**OP bei Kinderwunsch
patient:innenzentriert
abwägen**

Complementary therapeutic interventions

AWMF is the only guideline to address psychotherapeutic interventions in the context of fertility. It recommends CBT or mindfulness-based approaches, for patients with unfulfilled desire for children or undergoing fertility treatment, and routinely when infertility causes significant psychological distress.

For further detail on the level of evidence and strength of recommendation for infertility, please refer to Table 4-5.

AWMF:
begleitende
Psychotherapie bei
Belastungen durch
Kinderwunsch

Table 4-5: Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Do not use hormonal suppression to improve fertility	Strong/ ⊕⊕○○	Conditional/ ⊕⊕○○		—	Strong/ 1A
Post-op hormonal therapy if not immediately seeking pregnancy	Weak/ ⊕⊕○○	Strong/ ⊕⊕⊕○	—	—	—
Individual patient factors guide surgical decision-making (age, ovarian reserve, duration of infertility, pain, previous surgery, fertility investigations, EFI)	GPP (incl. EFI)	GPS (MDT + fertility specialist)	—	—	Best practice
Operative laparoscopy/excision or ablation for stage I-II endometriosis and infertility	Weak/ ⊕⊕○○	Conditional/ ⊕⊕○○	Strong/Very low (excision/ablation + adhesiolysis)	—	Strong/ 1A
Operative laparoscopy for endometrioma-related infertility	Weak/ ⊕○○○	—	Strong/very low	+++ (statement:)	Strong/ 1A
Discuss laparoscopic surgery for DIE: benefits and risks for fertility.	Weak/ ⊕○○○	Conditional/ ⊕⊕○○	Strong/very low	—	Weak/ 2B

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); DIE ... deep infiltrating endometriosis; EFI ... Endometriosis Fertility Index; ESHRE ... European Society of Human Reproduction and Embryology; GPP ... Good Practice Point; GPS ... Good Practice Statement; HSE ... Health Service Executive; incl ... inclusive; MDT ... multidisciplinary team; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.4 Recurrence of Endometriosis

Prevention of Recurrence

Postoperative hormonal suppression is recommended across guidelines for patients not immediately seeking conception, primarily to reduce symptom and endometrioma recurrence. Recommended options include CHCs, progestogens, LNG-IUS and, in some guidelines, GnRH agonists; ESHRE and AWMF place greater emphasis on longer-term treatment, while RANZCOG specifies at least 6-12 months after surgery. For recurrent pain, ESHRE allows either hormonal treatment or surgery, RANZCOG advises caution before repeat laparoscopy, and AWMF favours medical treatment over reoperation unless compelling surgical indications are present. Overall, guidance is consistent on recurrence prevention, while recommendations for treatment of recurrent symptoms are more heterogeneous and generally supported by weaker or consensus-based evidence.

For further detail on the level of evidence and strength of recommendation for recurrence, please refer to Table 4-6.

Hormonsuppression
leitlinienübergreifend
zur Rezidivprophylaxe
empfohlen

Table 4-6: Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Post-op hormonal therapy for recurrence prevention (not seeking pregnancy)	Strong/ ⊕○○○	Strong/ ⊕⊕⊕○	Weak/ Very low – moderate	++ (recommendation)	Strong/ 1A
Choice of agent: COC, progestogen, or GnRH agonist post-surgery	—	Strong/ ⊕⊕⊕○	Weak/ low to moderate (CHC noted; GnRH antagonist TAs)	++ (recommendation)	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); CHC ... Combined hormonal contraceptive; COC ... Combined oral contraceptive; ESHRE ... European Society of Human Reproduction and Embryology; GnRH ... Gonadotropin-releasing hormone; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; TA ... Treatment alternatives

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.5 Management of Asymptomatic Endometriosis

Asymptomatic endometriosis is addressed only by ESHRE, RANZCOG and AWMF; NICE and HSE provide no specific recommendations. ESHRE recommends counselling on incidental findings and advises against routine surgical or medical treatment, while ultrasound monitoring may be considered. RANZCOG recommends counselling on the low likelihood of progression with individualised follow-up, and AWMF advises against treatment of asymptomatic rectovaginal/vaginal or bowel endometriosis in the absence of relevant sequelae or fertility-related indications. Recommendation strength is generally strong or consensus-based, although certainty of evidence is low. NICE and HSE do not provide recommendations for the management of asymptomatic endometriosis

**asymptomatische
Endometriose nur
vereinzelt adressiert**

**keine Routinebehandlung
bei Zufallsbefunden**

For further detail on the level of evidence and strength of recommendation for the management of asymptomatic endometriosis, please refer to Table 4-7.

Table 4-7: Management of Asymptomatic Endometriosis:
Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
No routine surgery for asymptomatic endometriosis	Strong/ ⊕○○○	—	—	++ (recommendation)	—
No medical treatment for asymptomatic endometriosis	Strong/ ⊕○○○	—	—	—	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); ESHRE ... European Society of Human Reproduction and Embryology; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.6 Follow-up Care and Rehabilitation

NICE gives a weak recommendation for considering outpatient follow-up for patients with confirmed endometriosis, particularly those with DIE involving the bowel, bladder, or ureter, one or more endometriomas larger than 3 cm, or who choose not to have surgery. AWMF recommends that rehabilitation for patients with endometriosis should be conducted in a certified endometriosis rehabilitation facility. ESHRE, RANZCOG, and HSE do not provide specific recommendations on this topic in the sections reviewed.

For further detail on the level of evidence and strength of recommendation for the follow-up care and rehabilitation, please refer to Table 4-8.

Nachsorge & Rehabilitation
nur vereinzelt adressiert

Table 4-8: Follow-up Care and rehabilitation: Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE[33]	AWMF [34]	HSE [35]
Rehabilitation in a certified endometriosis rehabilitation facility	—	—	—	+++ (recommendation)	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); ESHRE ... European Society of Human Reproduction and Embryology; HSE ... Health Service Executive; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

4.2.7 Endometriosis in Adolescents

Overall, adolescent-specific guidance is broadly aligned in direction where provided, but coverage differs and recommendation strength and certainty of evidence vary across topics. Compared with adult care pathways, the adolescent-specific guidance focuses on earlier recognition of persistent pelvic pain, adapted examination and imaging approaches, cautious use of hormonal treatment, and referral to specialist care where appropriate. ESHRE and RANZCOG provide the most detailed diagnostic guidance, including alternative imaging where transvaginal ultrasound is not appropriate, while ESHRE and AWMF specify symptoms that should raise suspicion of endometriosis in adolescents. These include dysmenorrhoea and cyclical or acyclical pelvic pain, with AWMF emphasising persistent pelvic pain and ESHRE adding nausea, dyschezia, dysuria and dyspareunia. MDT composition across

Management otherwise broadly follows adult pathways, including the role of laparoscopy where imaging and conservative treatment are unsuccessful. Where adolescent-specific treatment guidance is provided, conservative medical treatment with hormonal contraceptives or progestogens is generally favoured as first-line management. RANZCOG additionally notes that intrauterine devices may require placement under general anesthesia.

ESHRE uniquely addresses fertility preservation counselling in adolescents with ovarian endometriosis, while RANZCOG and NICE support referral of adolescents with suspected or confirmed endometriosis to specialist care. HSE provides no adolescent-specific recommendations.

For further detail on the level of evidence and strength of recommendation for endometriosis in adolescents, please refer to Table 4-9.

frühe Erkennung &
angepasste Diagnostik im
Jugendalter in mehreren
Leitlinien adressiert

hormonelle Therapie
im Jugendalter vorsichtig
einsetzen

Überweisung Jugendlicher
in spezialisierte
Versorgung teilweise
unterstützt

Table 4-9: Adolescents: Key recommendation strength and quality of evidence across guidelines

Recommendations	ESHRE [31]	RANZCOG [32]	NICE [33]	AWMF [34]	HSE [35]
Assess risk factors + consider endometriosis with persistent pelvic pain, typical symptoms,	Strong/ ⊕○○○ (risk factors + symptoms)	—	—	+++ (recommendation)	—
TVUS if appropriate; otherwise transabdominal, transperineal, transrectal, or MRI	Strong/ ⊕⊕○○	Conditional/ ⊕⊕○○ (MRI/transperineal by specialist)	—	—	—
Laparoscopy if imaging and therapy fail; biopsy recommended; discuss timing with specialist; continue treatment while waiting	Weak/⊕⊕○○ (laparoscopy) Strong/⊕⊕○○ (biopsy)	GPS	—	+++ (recommendation) (diagnosis + surgical treatment)	—
First-line: hormonal contraceptives or progestogens; NSAIDs if needed; conservative medical treatment preferred.	Strong/ ⊕○○○ + GPP (NSAIDs)	Conditional/ ⊕⊕○○ (incl. IUD under GA)	—	+++ (recommendation)	—
Laparoscopic lesion removal followed by hormonal therapy to reduce recurrence.	Weak/⊕○○○ (surgery) Strong/⊕○○○ (post-op hormones) + GPP (laparoscopic)	—	—	+++ (recommendation) (simultaneous surgical treatment)	—
Refer adolescents (≤17) with suspected or confirmed endometriosis to specialist care.	—	GPS	Strong/ committee consensus	—	—

Abbreviation: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (engl. Working Group of Scientific Medical Societies); ESHRE ... European Society of Human Reproduction and Embryology; GA ... general anaesthesia; GnRH ... Gonadotropin-releasing hormone; GPP ... Good Practice Point; GPS ... Good Practice Statement; HSE ... Health Service Executive; IUD ... Intrauterine device; MRI ... Magnetic resonance imaging; NICE ... National Institute of Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; TVUS ... Transvaginal ultrasound

Legend: x/x = recommendation strength/evidence certainty; GPP/Good Practice Statement = expert consensus or good practice without formal evidence grading; — = no recommendation issued. For NICE, recommendation strength was inferred from recommendation wording rather than from an explicit grading category

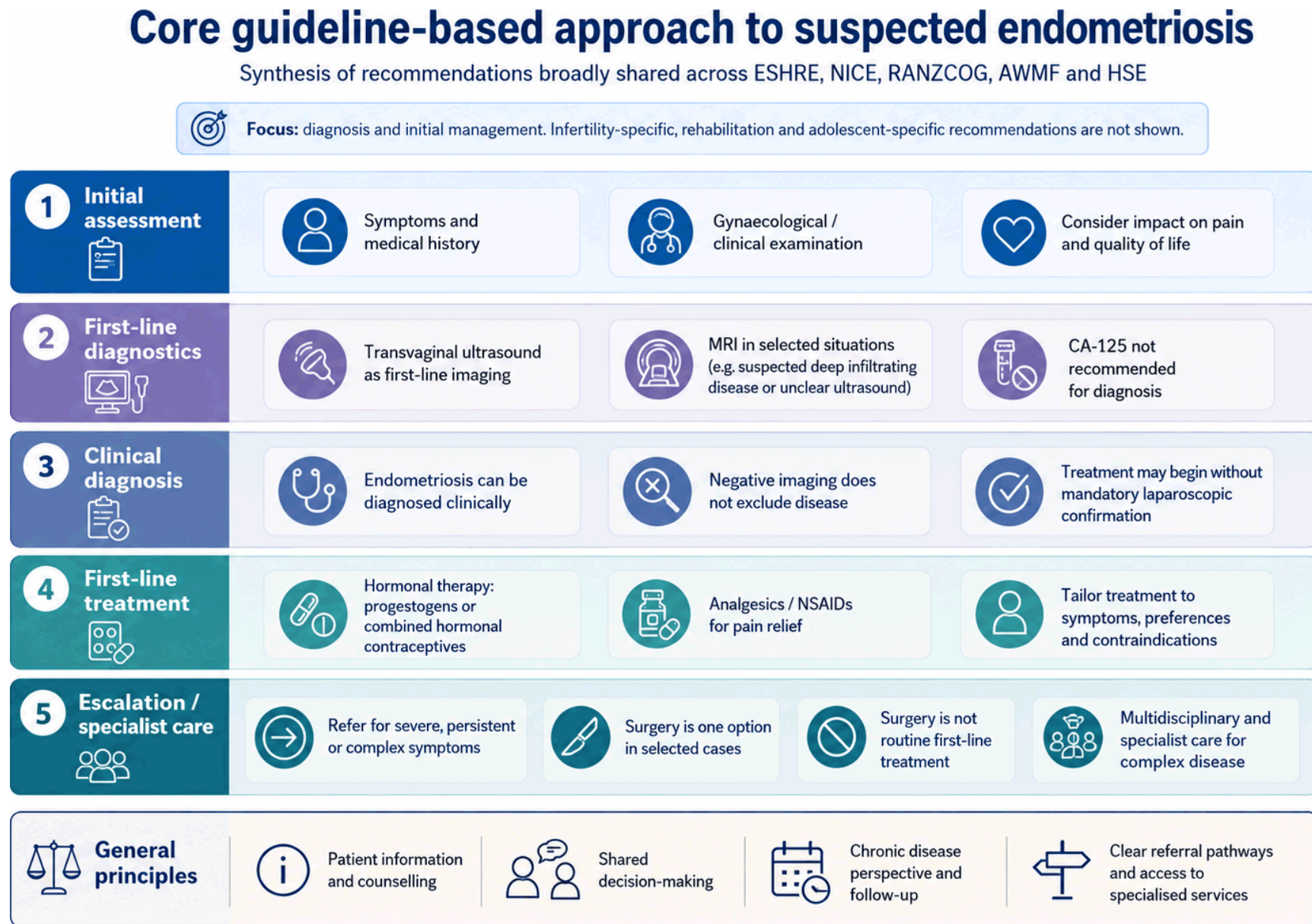


Figure 4-2: Core Guideline-based approach to suspect endometriosis

4.3 Organisation and Delivery of Endometriosis Care

This chapter presents findings on the organisation and delivery of endometriosis care, drawing on five international guidelines and three additional studies comprising a comparative analysis of endometriosis care in five high-income countries [27], a systematic review examining multidisciplinary care in endometriosis [36] and a framework describing the organisation of endometriosis care within the Irish healthcare system [37].

Leroy et al. [27] compared system-level organisation and delivery of endometriosis care in Australia, Denmark, Germany, the Netherlands, and the United Kingdom (UK). Fange et al. [36] systematically reviewed the role and organisation of multidisciplinary endometriosis care across healthcare settings, and the Irish framework [37] describes a national model for the organisation and delivery of endometriosis care. Findings are presented according to five key domains of care organisation and delivery identified across the included sources: coordinated and tiered care, referral pathways and access, multidisciplinary care, patient-centred care and shared decision-making, and quality assurance and professional training, where available. The characteristics and study design of additional literature identified on these domains are summarised in Table 4-10.

Versorgungsorganisation auf Basis von Leitlinien & ergänzender Literatur dargestellt

Table 4-10: Design of additional literature

Characteristics	Leroy et al. (2025) [27]	Fang et al. (2023) [36]	HSE (2025) [37]
Study Design	Comparative policy analysis	Systematic review	Tiered care framework
Country Setting	Australia, Denmark, Germany, Netherlands, UK	International	Ireland
Objective	Compare national endometriosis care structures and referral models	Identify MDT models used in practice and patient preferences	Define a structured endometriosis care pathway
Population	Women with endometriosis	Patients with endometriosis and/or chronic pelvic pain	Women with suspected or confirmed endometriosis
MDT-Approach	Mandatory only in selected countries and settings; not universally implemented	MDT central to holistic care; composition varies	Mandatory at regional and supra-regional level; specialist composition defined per tier
Limitations	Policy-level data; no outcome data; cross-country comparability limited by structural heterogeneity	Few studies; heterogeneity in outcome measures; limited generalisability	Implementation and outcomes not evaluated

Abbreviation: HSE ... Health Service Executive; MDT ... Multidisciplinary team; UK ... United Kingdom

Coordinated and Tiered Care

Across guidelines, endometriosis care is described as requiring coordinated care across different levels of the healthcare system, with escalation to specialist services according to disease complexity, treatment response and individual needs. NICE recommends managed clinical networks linking community, gynaecology and specialist services; community services include GPs, practice nurses, school nurses and sexual health services. AWMF similarly emphasises interdisciplinary networks involving specialised or certified centres, while RANZCOG highlights equitable access, including support for rural and remote care.

Leitlinien empfehlen koordinierte Versorgung mit bedarfsgerechter Überweisung an Spezialversorgung

International models reflect these principles to varying degrees. Tiered or specialised systems exist in several countries, but the degree of formalisation and centralisation differs [27]. Denmark, Germany and the Netherlands use tiered models with increasing concentration of complex care at specialist or reference centres, while the UK operates accredited tertiary centres without a formal secondary tier. Complex care is also provided outside designated centres in all countries. The HSE framework provides a particularly structured example, defining progression from primary and secondary care to regional and supra-regional specialist services, with increasing specialisation according to severity and complexity [37].

**internationale Modelle
unterschiedlich stark
formalisiert/zentralisiert**

**HSE-Modell als besonders
strukturiertes Beispiel**

Referral Pathways and Access

Guidelines support referral to specialist services for persistent or severe symptoms, treatment failure, fertility concerns and complex disease, particularly suspected or confirmed DIE requiring specialist surgical or multidisciplinary expertise. However, structured referral pathways between levels of care are often only broadly defined.

**Leitlinien empfehlen
Überweisung bei
Komplexität;
Pfade wenig definiert**

In practice, referral arrangements vary and are generally based on clinical judgement rather than formalised pathways [27]. Denmark is an exception, with mandatory referral of complex cases to tertiary reference centres. The HSE framework defines a structured escalation pathway across care levels, with referral based on symptom severity, treatment response, fertility concerns and disease complexity, including supra-regional [37].

**International meist
Überweisung nach
klinischem Ermessen;
Dänemark und Irland
mit klarer strukturierten
Pfaden**

Multidisciplinary Care

Guidelines consistently support multidisciplinary care, particularly for complex or persistent disease, although recommended team composition and the level of detail vary. Existing models show similar variation: MDT involvement is not routinely mandated in several countries, but Denmark and Germany require it for selected patients at higher levels of care [27]. The HSE framework similarly introduces MDT involvement progressively with increasing disease complexity [37].

**Leitlinien befürworten
MDT-Versorgung;
Einbindung international
unterschiedlich
verpflichtend geregelt**

The systematic review by Fang et al. found substantial variation in MDT composition across existing services, proposed care models and patient perspectives. Existing MDTs were mainly centred on gynaecology, physiotherapy and psychology, while proposed models included broader input from pain management, sex therapy, nutrition and social work. Patients particularly emphasised psychological support, physiotherapy, reliable information, validation and long-term support, but evidence on the impact of different MDT models remains limited [36].

**MDT-Zusammensetzung
international heterogen;**

**Evidenz zu optimalen
Modellen begrenzt**

Patient-centred Care and Shared Decision-making

Across guidelines, treatment decisions are generally framed as individualised, taking into account patient preferences, reproductive intentions, expected benefits and harms, costs and treatment availability. Where surgery is considered, ESHRE, RANZCOG and NICE additionally emphasise informed discussion of benefits, risks and longer-term consequences. Recommendations on shared decision-making are largely based on best-practice statements or expert consensus.

**Leitlinien empfehlen
individualisierte
Therapientscheidungen**

In practice, patient information is widely available but not consistently embedded within care pathways, and formal shared decision-making processes are only vaguely described [27, 37]. Patient perspectives prioritise reliable information, validation and involvement in care [36].

AWMF further recommends informing patients about self-help resources, education programmes, and available rehabilitation and support services. Inpatient rehabilitation concepts are not currently available in Austria and Switzerland; however, at least one specialised rehabilitation centre for endometriosis has since been established in Austria, offering an inpatient, multimodal programme combining peat bath therapy, physiotherapy, nutritional counselling, and pain management as a complementary, symptom-oriented intervention [38]. Evidence specific to endometriosis remains limited, and cost coverage by statutory health insurers is not standardly provided.

Broader support for the social and long-term impact of endometriosis also varies across countries. Denmark provides selected employment and financial support, while Australia offers eligible patients subsidized allied-health care through chronic disease management plans [27].

Quality Assurance and Professional Training

Guidelines provide little explicit guidance on quality assurance, auditing or professional training. Internationally, systematic data collection and training structures are also heterogeneous [27]. No comprehensive mandatory national registry was identified; Australia operates a voluntary national registry, while accredited UK centres collect standardised outcome data for severe cases. Specialist training is more structured in Denmark and linked to certification in Germany and the Netherlands, whereas primary care training remains limited overall [27]. The HSE framework includes training, research and follow-up among higher-tier functions but provides little detail on formal quality assurance or systematic data collection [37].

**Patient:inneninformation
verfügbar; Einbezug in
Entscheidungen wenig
strukturiert**

**spezialisierte Reha in
Österreich im Aufbau,
Evidenz & Kostendeckung
begrenzt**

**soziale/finanzielle
Unterstützung
international
unterschiedlich**

**Qualitätssicherung,
Datenerfassung und
Ausbildung international
unterschiedlich strukturiert**

5 Results: Empirical Studies

5.1 Patient Survey

The questionnaire was accessed 364 times and initiated 96 times. Of those who initiated the questionnaire, 21 respondents were excluded after a filter question indicated they were not currently receiving treatment in Vienna. After exclusion of ineligible and incomplete responses, 53 fully completed questionnaires were included in the final analysis. Consequently, all results are based on a sample size (n) of 53.

All additional figures from the patient survey that are not presented within the main text are provided in the Appendix.

Patient Sample and General Information

Respondents had a mean age of 31.2 years (SD 5.7; median 30; range 23-48), indicating a predominantly young adult sample. Participants were predominantly Austrian without a migration background, in full- or part-time employment, and comparatively highly educated, with the majority holding a university or applied sciences degree. Full sample characteristics are presented in Table 5-1.

Table 5-1: Patient Sample

Characteristics		n	%
Age	Mean (SD)	31.2 (5.7)	–
	Median (range)	30 (23-48)	–
Migration background	Austrian, no migration background	38	71.7
	Austrian, with migration history	7	13.2
	EU country of origin	5	9.4
	Multiple cultural backgrounds	3	5.7
Employment status	Full-time	18	34.0
	Part-time	15	28.3
	Other	10	18.9
	In training/education	6	14.0
	Self-employed	2	3.8
	Unemployed or looking for work	2	3.8
Education	University/applied sciences degree	33	62.3
	Secondary education (Reifeprüfung)	13	24.5
	Other	3	5.7
	Apprenticeship	2	3.8
	Compulsory schooling	1	1.9
	Secondary school without the Matura	1	1.9

Abbreviation: EU ... European Union; n ... number; SD ... Standard Deviation

Patient:innenbefragung:
53 vollständig ausgefüllte
Fragebögen

Alter, Herkunft,
Erwerbsstatus &
Bildungsniveau
der Befragten

Diagnostic Pathway and Care Setting

The mean time from first symptoms to diagnosis was 9.7 years (SD 7.4; median 9; range 0-30), indicating a long diagnostic pathway across the sample. Before diagnosis, most respondents had consulted three or more healthcare providers: 30.2% had seen 3-4 providers, 22.6% had seen 5-6, and a further 22.6% had consulted more than six; 22.6% had received a diagnosis after consulting only 1-2 providers.

Endometriosis was most commonly diagnosed in a non-specialised gynaecological practice (n=21; 39.6%), followed by a certified endometriosis centre or specialised clinic (n=16; 30.2%) and a non-specialised hospital setting (n=9; 17.0%). Seven respondents (13.2%) selected “other”, indicating heterogeneous diagnostic pathways.

Free-text responses under “endometriosis centre” included AKH Wien, Women & Health and Klinik Floridsdorf. This suggests that some respondents may have classified AKH Wien according to its specialist endometriosis function rather than as a university clinic. Seven respondents (13.2%) were not currently in treatment, while five (9.4%) selected other response options, including no answer or care across multiple settings.

At the time of the survey, the majority of respondents reported receiving treatment from a private gynaecologist (n=27; 50.9%), while nine (17.0%) were seen by a contracted gynaecologist. A smaller proportion were treated at an endometriosis centre (n=4; 7.5%) or hospital outpatient clinic (n=2; 3.8%).

Referral to a specialised centre following diagnosis or suspicion of endometriosis was reported by 28.3% of respondents; 69.8% reported no such referral. More than half reported a current or previous wish to conceive, which had been considered in their treatment for most of these respondents. Full details are shown in Table 5-2.

A large majority (n=44; 83%) reported periods during which they were unable to obtain help for their symptoms while only eight (15.1%) reported no such experience. Free-text responses identified dismissal of symptoms as the most prominent barrier, with many respondents reporting that pain had been repeatedly characterised as normal or exaggerated by healthcare providers. Further recurring themes included diagnostic uncertainty or inconclusive findings, inadequate follow-up, symptomatic treatment without further investigation, long waiting times, limited availability of specialists, and insufficient provider knowledge of endometriosis.

**Ø 9,7 Jahre
bis zur Diagnose & oft
>3 konsultierte Ärzt:innen**

**Diagnosestellung
am häufigsten in Praxen
ohne Endometriose-
Schwerpunkt**

**Behandlung erfolgt
selten in spezialisierten
Endometriosezentren**

**aktuelle Behandlung
überwiegend bei privaten
Gynäkolog:innen (≈ 51 %)**

**Kinderwunsch bei mehr als
der Hälfte der Befragten**

**83 % berichteten
über Zeiträume
ohne ausreichende
Unterstützung**

**Symptome wurden
häufig heruntergespielt**

Table 5-2: Diagnostic pathway and care setting

Indicator	Category	n	%
Time to diagnosis	Mean (SD)/Median (range), years	9.7 (7.4)	9 (0-30)
Providers consulted before diagnosis	1-2	12	22.6
	3-4	16	30.2
	5-6	12	22.6
	>6	12	22.6
Setting of diagnosis	Non-specialised gynaecological practice	21	39.6
	Certified endometriosis centre/specialised clinic	16	30.2
	Non-specialised hospital	9	17.0

Indicator	Category	n	%
Current care setting	Private gynaecologist	27	50.9
	Panel/contracted gynaecologist	9	17.0
	Not currently in treatment	7	13.2
	Endometriosis centre	4	7.5
	Hospital outpatient clinic	2	3.8
Referral to specialised centre after diagnosis	No	37	69.8
	Yes	15	28.3
Wish to conceive (current/previous)	Yes	28	52.8
considered in treatment	Yes	20/28	71.4

Abbreviation: n ... number; SD ... Standard Deviation

Symptoms Prior to Diagnosis

Pain-related and systemic symptoms dominated the pre-diagnostic picture: severe menstrual pain (92.5%), fatigue and exhaustion (86.8%), and digestive problems (73.6%) were the most frequently reported symptoms, followed by psychological burden, chronic lower abdominal pain, and pain during intercourse. Free-text responses added further symptoms not captured by the standard categories, including migraine, back and leg pain, bladder pain, and rectal bleeding, underlining the broad and often atypical symptom spectrum preceding diagnosis. Full frequencies are shown in Figure 5-1.

**breites Symptomspektrum
vor der Diagnose**

**starke
Menstruationsschmerzen
bei über 90 %**

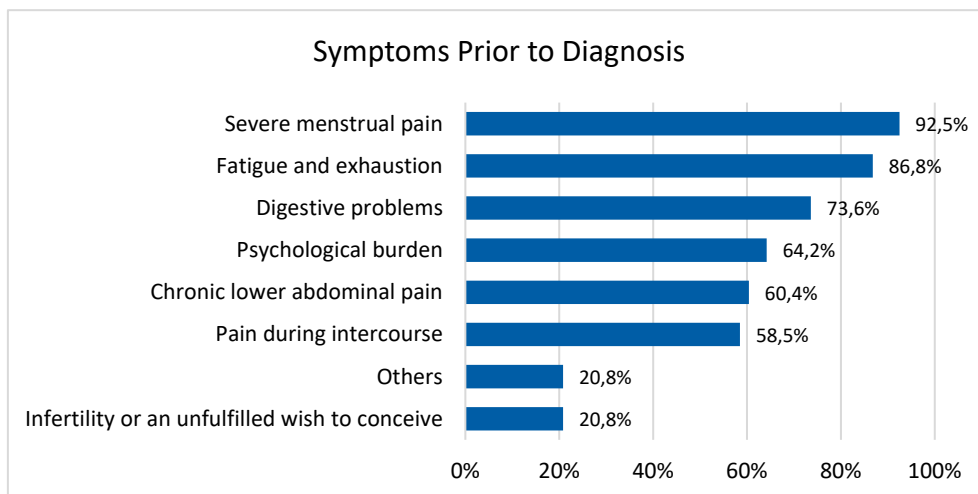


Figure 5-1: Symptoms Prior to Diagnosis

Initial Investigations and Follow-Up

The three most frequently reported initial investigations were ultrasound (n=42; 79.2%), gynaecological/vaginal examination (n=35; 66.0%) and blood tests (n=12; 22.6%); further details are shown in Figure 5-2. When these initial investigations were unremarkable but symptoms persisted, further management had not been clearly discussed with a large percentage of respondents (n=31; 58.5%).

**Erstuntersuchungen
v. a. Ultraschall &
gyn. Untersuchung;
weiteres Vorgehen
bei rund 60 % unklar**

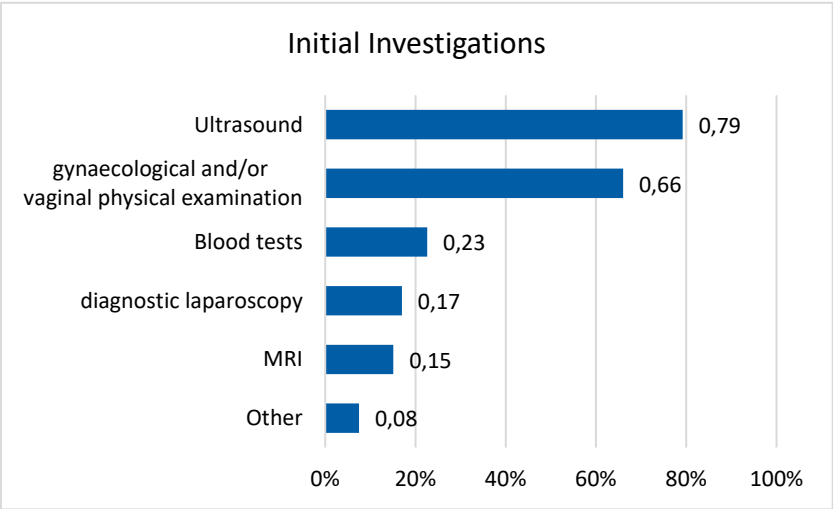


Figure 5-2: Initial Investigations

First-Line and Additional Treatments Received

Hormonal treatment was the most common first-line therapy (n=31; 58.5%), followed by pain medication or surgery, while non-pharmacological approaches such as physiotherapy were rarely used initially

Beyond first-line management, respondents reported a broad range of additional therapies. Pain medication was the most widely used treatment overall (n=47; 88.7%), and physiotherapy, psychological support and alternative therapies were each used by roughly half of respondents. (see Figure 5-3 and Figure 5-4 for the full comparison across all treatment categories).

hormonelle Therapie häufigste Erstbehandlung (58,5 %); operative & komplementäre Ansätze deutlich seltener

zusätzliche Behandlung v. a. Schmerzmedikation (≈ 89 %)

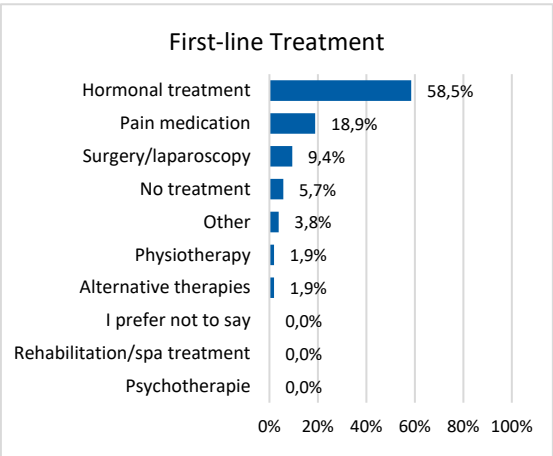


Figure 5-3: First-line Treatments

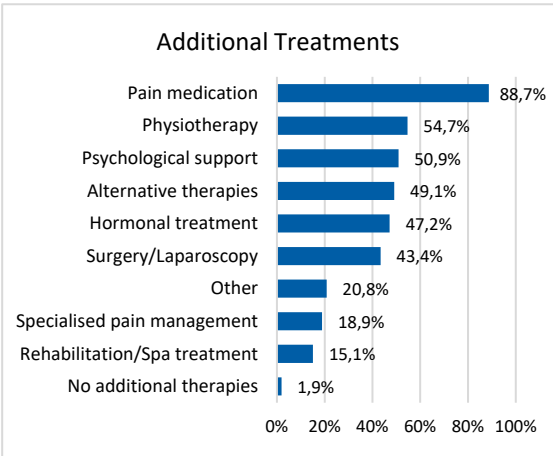


Figure 5-4: Additional Treatments

Out-of-Pocket Costs

The large majority of respondents (n=47; 88.7%) reported having incurred costs not covered by statutory health insurance, with a third of them exceeding €5,000 (n=18; 34.0%). Only six (11.3%) reported no additional costs. Private gynaecological consultations and specialist fees were the most frequently reported out-of-pocket expenses, followed by a range of supportive and complementary treatments. Respondents also reported costs for medication, fertility treatment and diagnostic investigations, sometimes in connection with long waiting times in the statutory system. Table 5-6 shows exact estimated expenditure amounts.

Satisfaction with current treatment was limited: only around a fifth reported being (very) satisfied, while partial satisfaction was most common (n=23; 43.4%).

rund 89 % berichten nicht durch SV gedeckte Kosten; 1/3 der Pat.: Ausgaben über €5,000

Zufriedenheit mit aktueller Behandlung z. T eingeschränkt

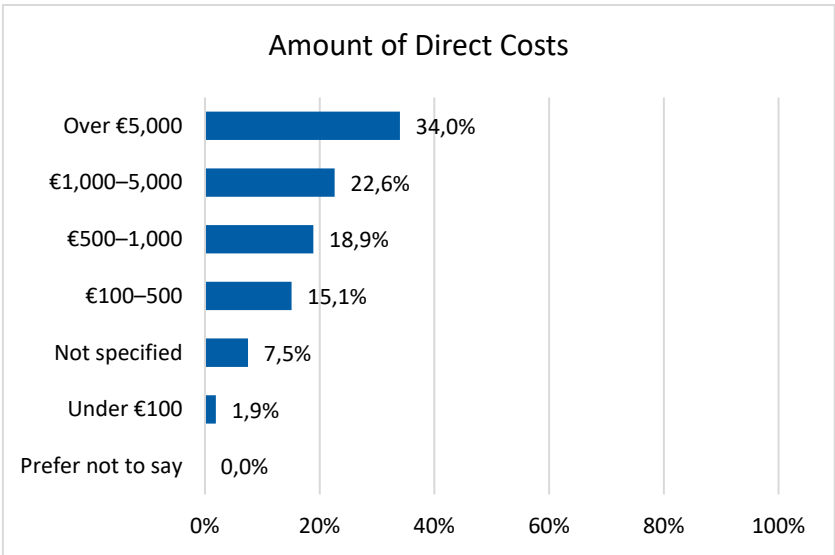


Figure 5-5: Amount of direct cost

Information and Awareness

Respondents most commonly reported having received information on available treatment options and on the stage and extent of their endometriosis, while broader aspects of long-term disease management, such as side effects and self-help resources, were addressed far less consistently (see Figure 5-6 for the full breakdown).

When asked about shared decision-making experiences., around half of respondents (n=25; 47.2%) felt included in treatment decisions, while just under a third (n=15; 28.3%) did not. Self-perceived knowledge of endometriosis was comparatively high, with the large majority (n=42; 79.2%) reporting that they felt well or very well informed.

Informationen v. a. zu Behandlungsoptionen & Langzeitmanagement nicht thematisiert

knapp die Hälfte in Behandlungsentscheidung einbezogen; subjektiver Informationsstand hoch

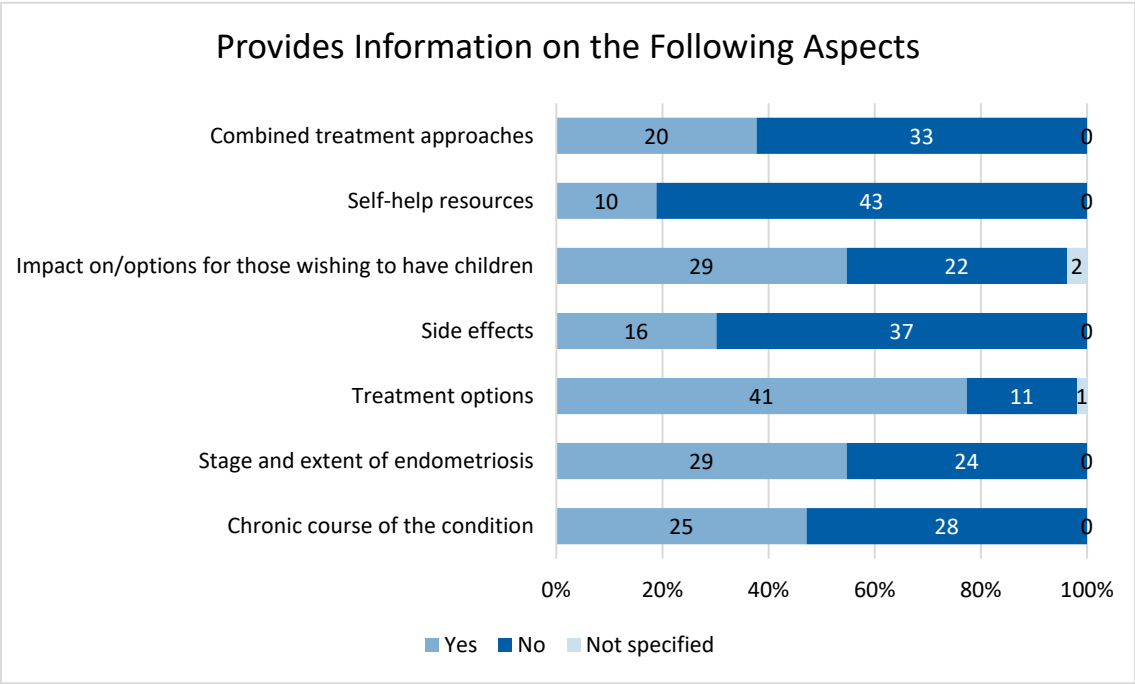


Figure 5-6: Information provided for patients

Gaps in Information and Patient Support

Free-text responses (n=32) pointed to recurring gaps in information, communication and support. Respondents described insufficient information on the broader manifestations of endometriosis, treatment options beyond hormonal therapy, and fertility preservation, leading many to seek information independently or through patient support groups. Post-operative follow-up was also described as insufficient, particularly regarding explanation of findings, recovery and further management. More broadly, respondents reported conflicting advice, limited provider knowledge and difficulties accessing specialist or interdisciplinary care.

Pat. Berichten von Informations-, Kommunikations- und Nachsorgelücken;

erschwerter Zugang zu spezialisierter Versorgung

Challenges in Living with Endometriosis

Psychosocial Impacts

Endometriosis was reported to have a broad impact across multiple life domains, most frequently psychological health (n=48; 90.6%), followed by sexual life, social relationships, professional career, and family planning. Further responses are shown in Figure 5-7.

weitreichende Auswirkungen auf psychische Gesundheit (≈ 91 %), Sexualleben & soziale Beziehungen

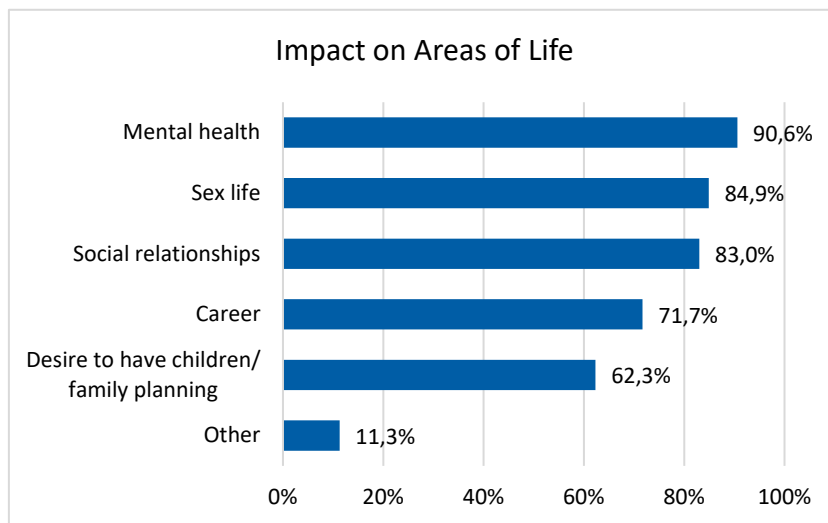


Figure 5-7: Impacts on Areas of Life

Experiences of symptom dismissal were common. Nearly two-thirds indicated that this had occurred very often (n=33; 62.3%), followed by often (n=14; 26.4%) and sometimes (n=4; 7.5%). Only two respondents (3.8%) reported never having felt that their symptoms were insufficiently acknowledged by healthcare providers.

Free-text responses on daily life with endometriosis (n=40) most frequently referred to chronic and unpredictable pain, including painful periods, bowel-related symptoms (“endo belly”), pelvic floor spasms, and pain occurring alongside work, study, and family obligations; several responses described this pain having been normalised for years after being told it was typical period pain.

Further recurring themes included experiences of not being taken seriously by healthcare providers, family, or friends, including comments regarding age or suggestions that pregnancy would improve symptoms, in some cases continuing after surgery; the need to independently research treatment options and identify providers; barriers relating to waiting times and differences in access between publicly and privately funded care; uncertainty regarding fertility and pressure to attempt conception earlier than planned; sexual dysfunction, including pain during intercourse and reduced libido; occupational and social impacts, including reduced working hours and reduced social contact; and psychological burden, including anxiety and distress related to a chronic and unpredictable illness. The financial burden and limited access to treatment, as well as the need to take pain seriously and the importance of rehabilitation, were raised once again.

What Is Already Working Well in Care

Free-text responses on what was already working well in care (n=46) highlighted several positive aspects. Respondents most often described specialised medical competence and empathetic care, including appropriate referrals, feeling taken seriously, thorough explanations, and access to physicians familiar with endometriosis and advanced diagnostic equipment. Positive treatment experiences were also reported, including symptom relief through hormonal treatment, surgery, and physiotherapy, as well as increasing acceptance of ultrasound-based diagnosis.

fast alle erlebten zumindest gelegentlich, dass ihre Beschwerden nicht ernst genommen wurden; 62 % sehr häufig

chronische, unvorhersehbare Schmerzen prägen den Alltag

mangelnde Anerkennung, Versorgungsbarrieren und psychosoziale Belastungen

positive Erfahrungen v. a. spezialisierte, empathische Versorgung und wirksame Behandlung

Further positive themes included growing public and professional awareness of endometriosis, access to specialised care structures such as endometriosis centres, rehabilitation programmes, and insurance coverage for specialist care. Self-help groups, online communities, patient associations, and conferences were also described as important sources of information and support, helping some respondents improve coping, pain management, and navigation of the healthcare system.

wachsende öffentliche & fachliche Aufmerksamkeit sowie wichtige Rolle von Selbsthilfegruppen & Patient:innen-organisationen

Overall Rating of Healthcare Provision

Respondents rated six aspects of endometriosis-related healthcare on a scale from 1 (very good) to 5 (very poor). As these are ordinal data, the median rather than the mean is reported as the primary measure (see Figure 5-8 for the full distribution). Psychosocial support, reimbursement of treatment costs, and availability of treatment options and waiting times received the poorest ratings (median 4.0 each, with 37 respondents assigning a score of 4 or 5 in each domain), while access to specialists and education/information were rated somewhat more favourably (median 3.0 each); negative assessments nonetheless predominated across all six domains.

**Versorgung insgesamt
Psychosoziale
Unterstützung und
Versorgungszugang
besonders schlecht
bewertet**

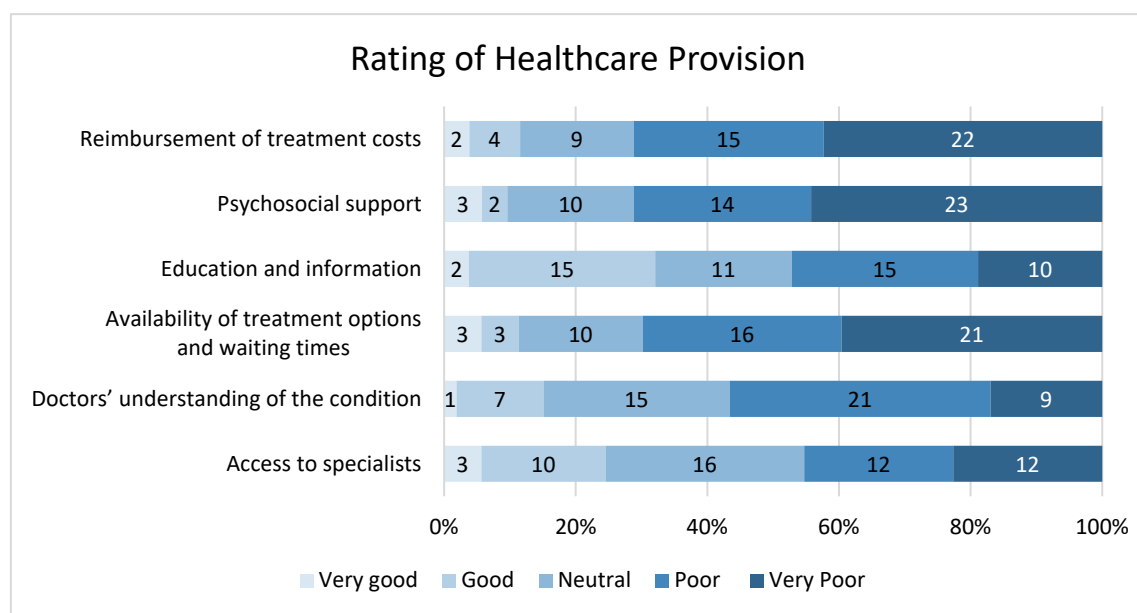


Figure 5-8: Rating of Healthcare Provision

5.2 Healthcare Provider Survey

The questionnaire was accessed 254 times, initiated 85 times, and completed in full by 49 respondents. Incomplete questionnaires were excluded from the final analysis to ensure consistent results and a constant sample size (n). Consequently, all results are based on a sample size (n) of 49.

All additional figures from the healthcare provider survey that are not presented within the main text are provided in the Appendix.

General Information

Respondents worked predominantly in office-based settings, most commonly in private practice (n=27; 54.0%) or contracted practice (“Kassenpraxis”) (n=16; 32.0%), while hospital and university-based settings were less represented. Only nine respondents (18.4%) reported affiliation with a certified endometriosis centre, while the large majority (n=39; 79.6%) did not. Most respondents reported seeing six to 15 endometriosis patients per month (n=20; 40.8%), followed by zero to five patients (n=18; 36.7%). Further details in Table 5-3.

Table 5-3: General Information

Topic	Category	n	%
Practice setting (multiple response, n=49)	Private practice	27	54.0
	Panel/contracted practice (“Kassenpraxis”)	16	32.0
	Hospital	6	12.0
	University clinic	5	10.0
	Multiple settings selected	6	12.0
Certified endometriosis centre	Affiliated	9	18.4
	Not affiliated	39	79.6
	No answer	1	2.0
Monthly endometriosis patients	0-5	18	36.7
	6-15	20	40.8
	>15	11	22.4

Abbreviation: n ... number

Available Services

Pharmacological therapy, ultrasound and pain management were listed as available in-house in almost every setting, while MRI, pelvic floor physiotherapy and diagnostic surgery were all predominantly accessed externally. Psychosocial services showed the greatest gaps in availability, with psychological/psychosomatic care and sexual medicine counselling frequently reported as unavailable. For further details see Figure 5-9.

Gynäkolog:innen-
befragung:
49 vollständig ausgefüllte
Fragebögen

Überwiegend
niedergelassene
Gynäkolog:innen;
nur 18 % mit Anbindung
an zertifiziertes
Endometriosezentrum

medikamentöse Therapie,
Ultraschall & Schmerz-
behandlung überwiegend
intern verfügbar;
MRT, Physiotherapie &
operative Leistungen
meist extern;
psychosoziale Angebote
teilweise überhaupt nicht
verfügbar

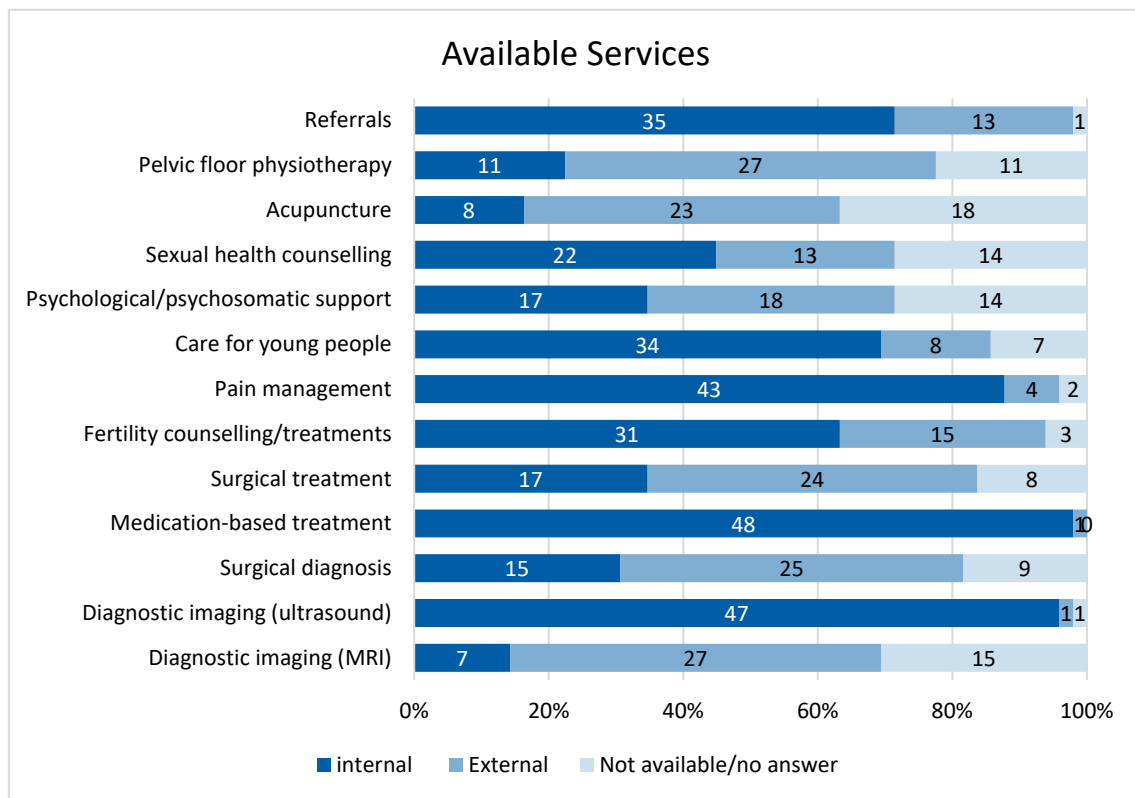


Figure 5-9: Available Services

Diagnostic Practice

Structured Pathway for Suspected Endometriosis

A formally documented pathway for suspected endometriosis was reported in only eight practices (16.3%); most respondents relied on an informal approach (n=28; 57.1%), while eleven (22.4%) reported no structured pathway. Where pathways existed, they were based mainly on individual clinical experience (n=17; 41.5%) and, to a lesser extent, international guidelines (n=12; 29.3%), particularly AWMF S2k and ESHRE. International guidelines were nevertheless viewed positively overall, with 77.6% (n=38) of respondents rating them as helpful or very helpful. Full details are shown in Table 5-4.

**formal dokumentierter
Versorgungspfad bei
Endometrioseverdacht nur
in 16 % der Praxen**

Table 5-4: Diagnostic Practice

Topic	Category	n	%
Care pathway for suspected endometriosis	Informal	28	57.1
	Formally documented	8	16.3
	None	11	22.4
	Unsure	2	4.1
Basis of pathway (n=41)	Clinical experience	17	41.5
	International guidelines	12	29.3
	Team discussion	4	9.8
	In-house standards	2	4.9
	Other/no answer	7	17.1

Topic	Category	n	%
Perceived usefulness of international guidelines	Very helpful	25	51.0
	Helpful	13	26.5
	Neutral	10	20.4
	Unfamiliar	1	2.0

Abbreviation: n ... number

Diagnostic Work-up

Diagnostic procedures used when endometriosis was suspected were assessed as a multiple-response item; History-taking and gynaecological examination, alongside transvaginal ultrasound, were reported almost universally (n=49; 100.0% and n=47; 95.9%, respectively). MRI in cases of suspected deep infiltrating endometriosis was reported by 30 respondents (61.2%), while diagnostic laparoscopy was reported by 19 (38.8%). (see Figure 5-10) All respondents reported using transvaginal ultrasound as first-line investigation. When asked about MRI indications, suspected deep infiltrating endometriosis (n=30; 65.2%) and unclear ultrasound findings (n=29; 63.0%) were most commonly reported; none reported routine MRI use in all patients.

**Basisdiagnostik
meist mit Anamnese,
gyn. Untersuchung
und TVUS;
MRT gezielt,
Laparoskopie seltener**

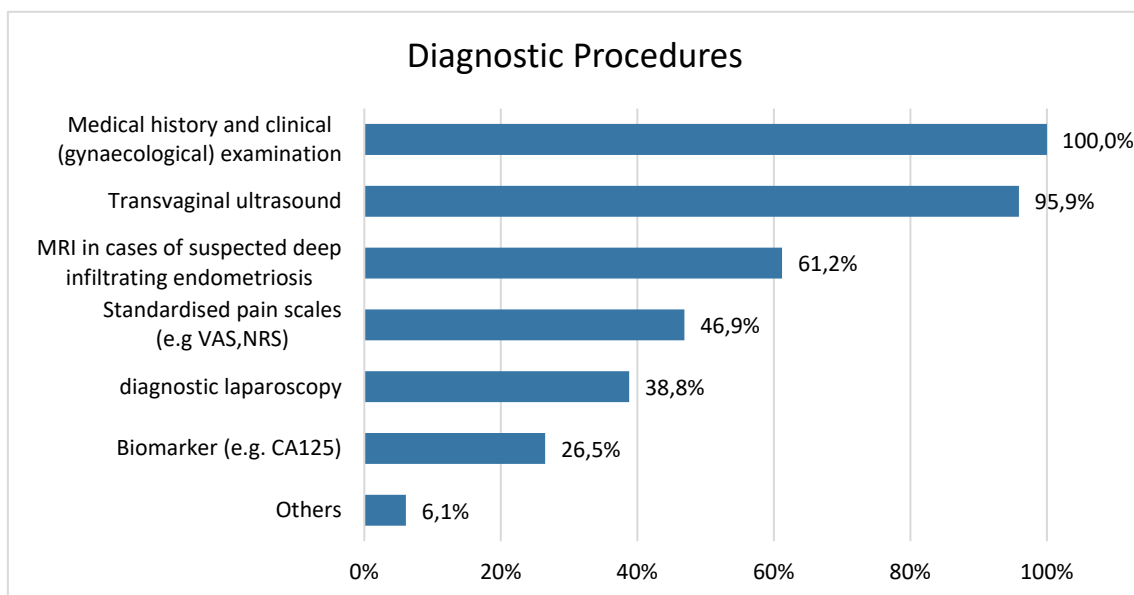


Figure 5-10: Diagnostic Procedures in suspected endometriosis

Working Diagnosis and Use of Diagnostic Laparoscopy

Around two-thirds of respondents reported routinely or frequently making a clinical working diagnosis of endometriosis without diagnostic laparoscopy (n=34; 69.4%), while the remainder reported doing so occasionally or rarely.

Consistently, no respondent applied it routinely in clinical practice, and 19 (38.8%) did not use it for diagnostic purposes at all. When used, it was most commonly considered after inconclusive non-invasive assessment or for diagnostic confirmation in cases of clinical suspicion (n=16; 32.7% each).

**klinische Arbeitsdiagnose
häufig;
diagnostische
Laparoskopie nur
selektiv eingesetzt**

Use of Standardised Classification Systems (rASRM/Enzian)

Routine use of a standardised classification system (rASRM or Enzian) was reported by 21 respondents (42.9%), with a further nine (18.4%) reporting frequent use.

Further details across diagnostic practice items are summarised in Table 5-5.

Klassifikationssysteme bei rund 60 % regelmässig angewendet

Table 5-5: Diagnostic Work-Up

Topic	Category	n	%
Working diagnosis without laparoscopy	Routinely	14	28.6
	Frequently	20	40.8
	Occasionally	9	18.4
	Rarely	6	12.2
Use of diagnostic laparoscopy	Not used diagnostically	19	38.8
	Unclear findings	16	32.7
	Diagnostic confirmation	16	32.7
	Other circumstances	8	16.3
Standardised classification, surgical cases	Routinely	21	42.9
	Frequently	9	18.4
	Not applicable	10	20.4
	Occasionally/rarely	8	16.3

Abbreviation: n ... number

Competencies Considered Important for High-Quality Diagnosis

Free text responses on competencies required for high-quality diagnosis focused primarily on sonographic expertise, supported by dedicated training, certification and continuing education. A second recurring theme concerned comprehensive clinical assessment, particularly thorough history-taking and gynaecological examination, alongside clinical experience. Further themes included competence in interpreting MRI findings and laparoscopic skills for complex or unclear cases, as well as structural conditions supporting diagnostic quality, such as interdisciplinary collaboration, sufficient consultation time and clear referral pathways to specialised centres.

Ärzt:innen betonen sonografische Expertise und klinische Erfahrung als zentral für diagnostische Qualität

Therapy

First-Line Treatment for Symptomatic Endometriosis Without a Wish to Conceive

For patients without a current wish to conceive, progestogen-only therapy was the most commonly reported first-line option (n=26; 53.1%), followed by combined hormonal contraceptives (n=12; 24.5%). No respondent reported surgery as first line treatment. The full distribution of responses is shown in Figure 5-11.

Erstlinientherapie bei Pat. ohne Kinderwunsch v. a. Gestagene und kombinierte hormonelle Kontrazeptiva

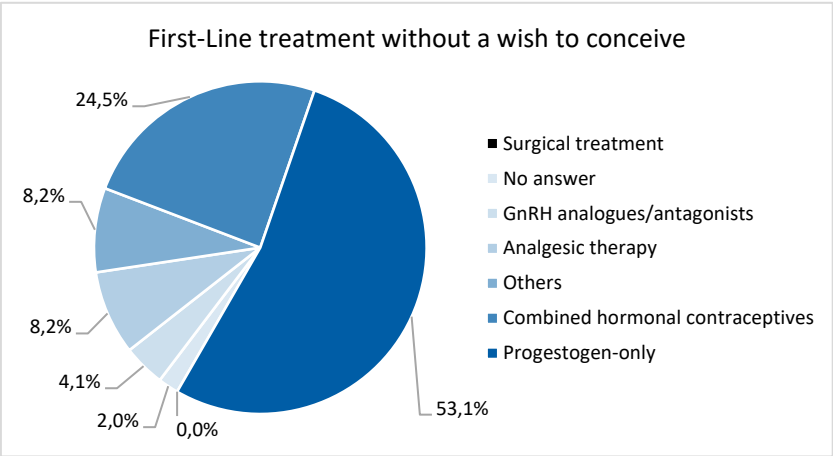


Figure 5-11: First line treatment in patients without a current wish to conceive

Surgical therapy was considered primarily when pain persisted despite conservative treatment (n=37; 75.5%), and, in roughly half of practices, also for suspected deep infiltrating disease (n=28; 57.1%); further indications are shown in Figure 5-12.

OP v. a. bei persistierenden Schmerzen; auch bei Verdacht auf DIE

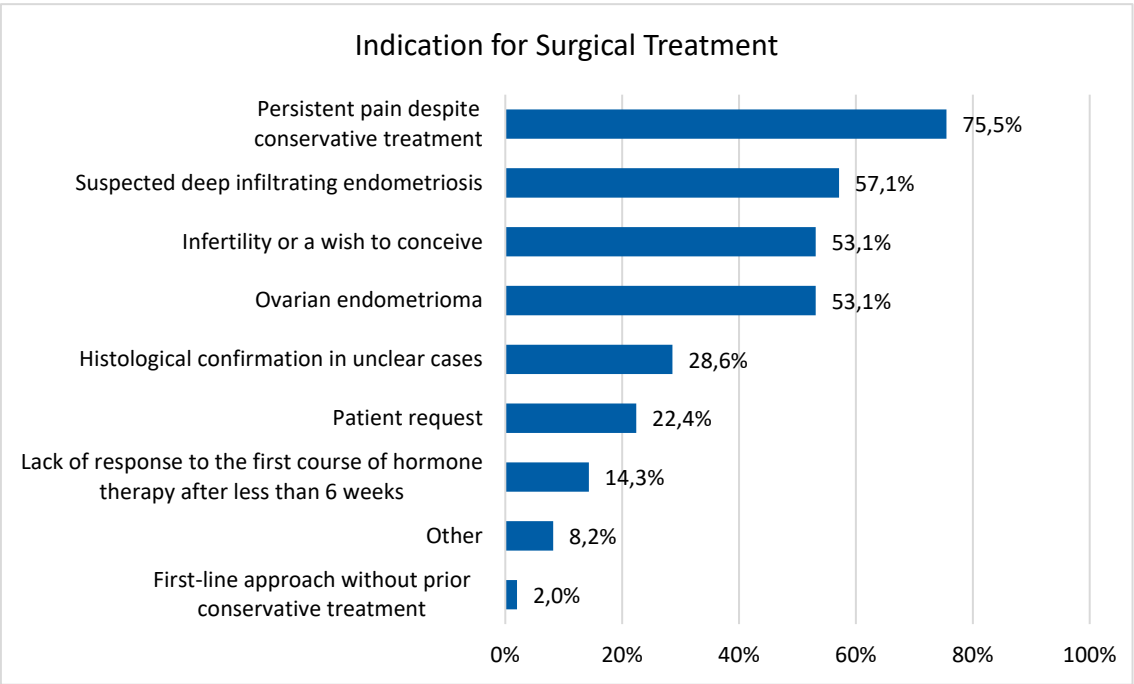


Figure 5-12: Indication for Surgical Treatment

Respondents reported spending an average of 22 minutes on treatment decisions (median 20 minutes, n=44), and most considered this sufficient (n=32; 72.7%). However, several respondents noted that this time is not reimbursed accordingly within the statutory insurance system.

Ø 22 Min. für Therapieentscheidungen

Multidisciplinary Care

Structured Interdisciplinary Collaboration

Structured interdisciplinary collaboration was reported as regularly established by 15 respondents (30.6%) while a further 22 (44.9%) described informal collaboration on an as-needed basis. Ten respondents (20.4%) reported no such collaboration.

Reproductive medicine was the most frequently cited discipline (n=26; 55.3%), followed by radiology (n=22; 46.8%); further disciplines are shown in Figure 5-13.

**interdisziplinäre
Kooperation bei
¼ der Befragten**

**regelmäßige
Zusammenarbeit v. a. mit
Reproduktionsmedizin &
Radiologie**

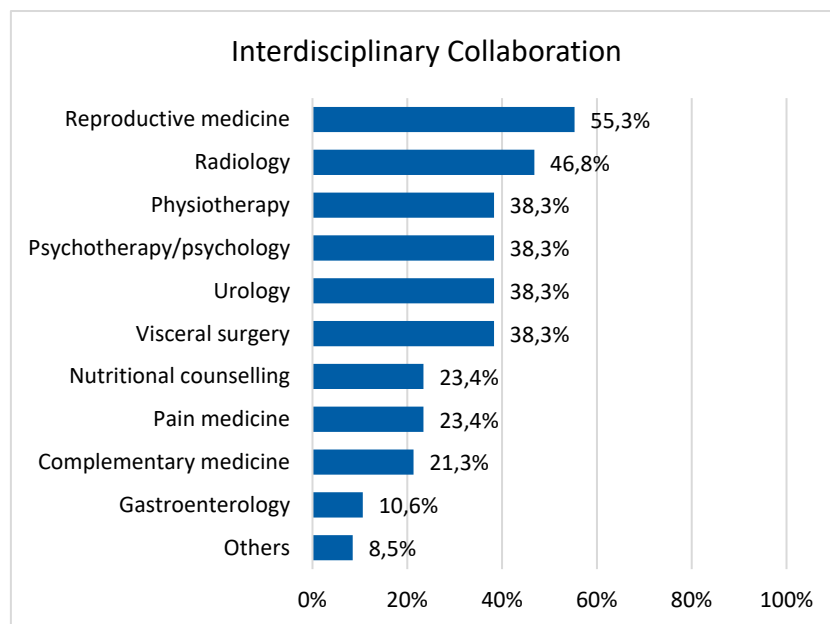


Figure 5-13: Interdisciplinary Collaboration

Management of complex cases was assessed by multi-response items. Referral to a specialised centre was most commonly reported (n=37; 75.5%), followed by collaboration with specialised surgical disciplines such as colorectal surgery (n=20; 40.8%). In-house surgical management by the respondent's own gynaecological team was less common (n=7, 14.3%).

**komplexe Fälle meist über
spezialisierte Zentren &
chirurgische Kooperation
versorgt**

Fertility-Related Counselling and Preferred Management Strategy

Fertility-related counselling was widely provided for patients with a wish to conceive, 35 respondents (71.4%) always provided such counselling and 14 (28.6%) mostly did so; none reported providing it rarely or never. Early referral to or involvement of reproductive medicine was the most frequently reported strategy (n=20; 40.8%), followed by an individualised approach without a uniform protocol (n=11; 22.4%); further strategies are shown in Table 5-6.

**Fertilitätsberatung
nahezu durchgängig;
häufig frühe Einbindung
der Reproduktionsmedizin**

Adolescent patients received adapted treatment and/or referral in just over half of practices (n=27; 55.1%), while nine respondents (18.4%) reported managing them no differently from adults, and seven (14.3%) did not treat adolescent patients at all.

**55 % der jugendlichen Pat.
erhalten angepasste
Behandlung und/oder
Weiterleitung**

Further details on fertility-related management strategies and care of adolescent patients are summarised in Table 5-6.

Table 5-6: Fertility Management

Topic	Category	n	%
Fertility counselling (wish to conceive)	Always	35	71.4
	Mostly	14	28.6
Preferred fertility strategy	Early referral to reproductive medicine	20	40.8
	Individualised, no uniform protocol	11	22.4
	Combined operative/reproductive approach	9	18.4
	Conservative-first	7	14.3
Adolescent patients	Adapted management and/or referral	27	55.1
	Managed as adults	9	18.4
	Not managed in this practice	7	14.3
	Specific referral; treatment remains the same	4	8.2
	No information provided	2	4.1

Abbreviation: n ... number

Care provision Structure and Framework Conditions

Structural Barriers, Guideline Discrepancies, and Proposed Improvements

Structural barriers were assessed as a multiple-response item. Among the 44 respondents answering this item, time constraints in clinical practice were selected most frequently (n=19; 43.2%), followed by long waiting times (n=18; 40.9%) and limited surgical capacity (n=17; 38.6%); further responses to barriers are shown in Figure 5-14.

**häufigste strukturelle
Hürden: Zeitmangel im
klin. Alltag, lange
Wartezeiten &
eingeschränkte
OP-Kapazitäten**

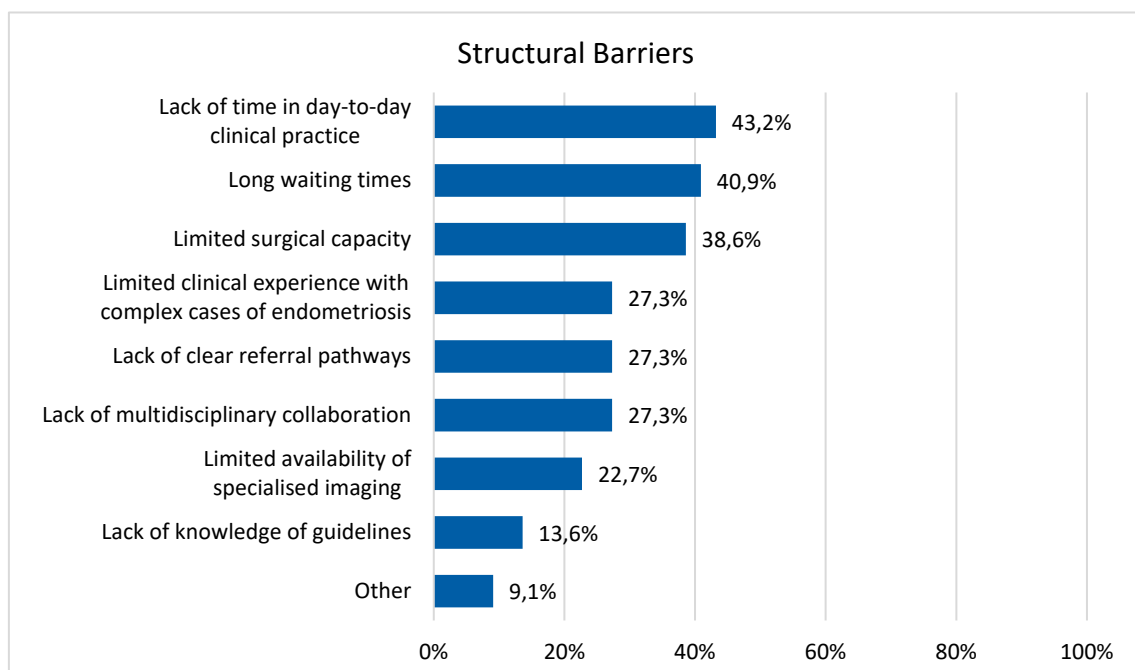


Figure 5-14: Discrepancies between guidelines and practice

Among the 46 respondents who answered the item on discrepancies between guideline recommendations and clinical practice, multidisciplinary collaboration was most frequently selected (n=20; 43.5%), followed by diagnostics, including imaging and classification (n=19; 41.3%); further categories are shown in Figure 5-15. Free-text comments highlighted long waiting times for specialised outpatient clinics, the lack of a dedicated endometriosis centre in Vienna, and limited access to referral findings through ELGA.

größte Abweichungen zwischen Leitlinien & Praxis bei multidisziplinärer Zusammenarbeit sowie Diagnostik

Among the 48 respondents answering the item on measures to improve endometriosis care, expansion of certified endometriosis centres was the most frequently selected measure (n=28; 58.3%), followed by improved training and continuing education (n=23; 47.9%); further measures are shown in Figure 5-16.

Verbesserungsbedarf v. a. bei Ausbau zertifizierter Zentren sowie Fort- und Weiterbildung

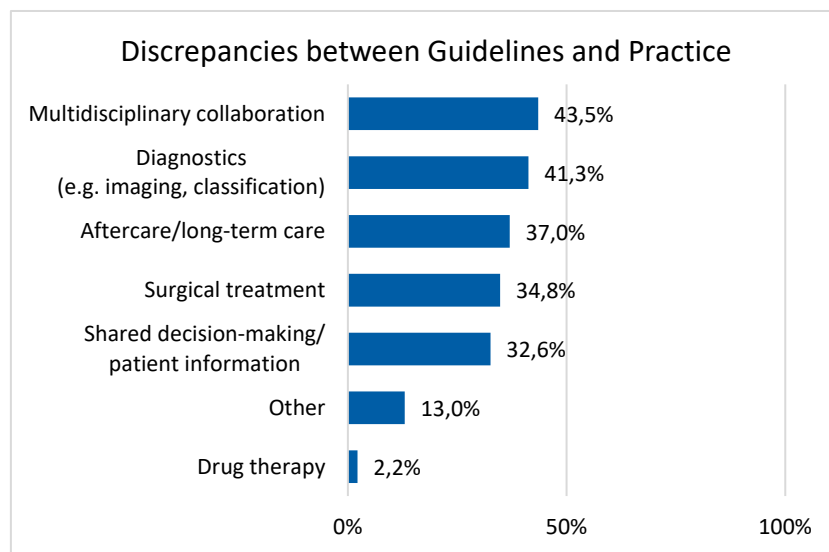


Figure 5-15: Discrepancies between guidelines and practice

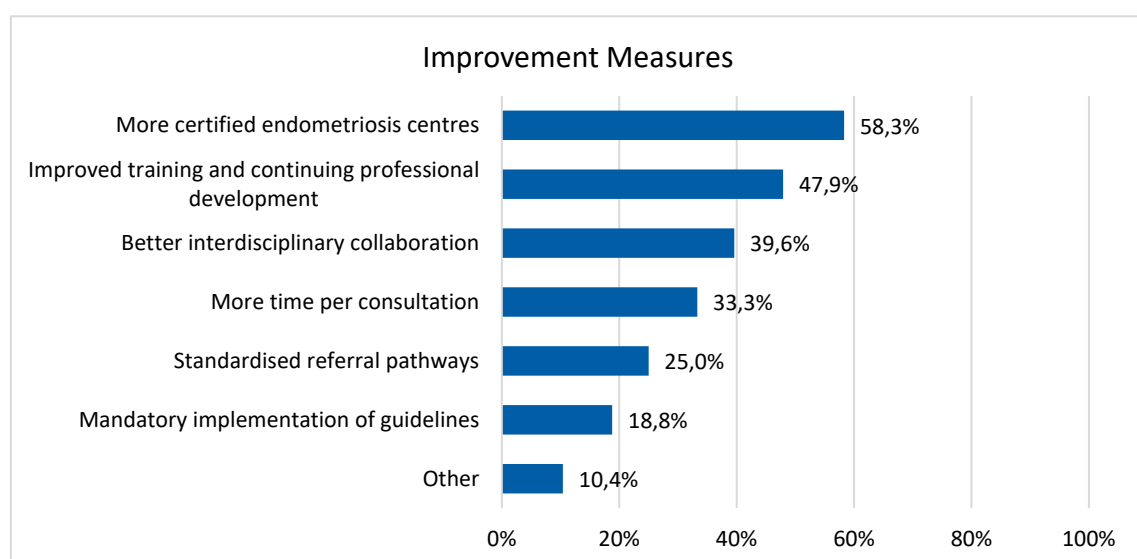


Figure 5-16: Measures of Improvement

System-Specific Factors Influencing Endometriosis Care in Vienna

Among the 35 respondents who provided a response, many gave no substantive Vienna-specific comment. Those who did mainly reiterated previously identified issues; additional points included differences between statutory and private care, patients travelling from other federal states, and occasional concerns about over-diagnosis, trivialisation and insufficient patient education.

Of the 37 respondents who identified areas for improvement, most again converged on measures already discussed above, particularly the need for more specialised centres, shorter waiting times, better training, and improved remuneration. A further recurring point was the need for clearer, standardised referral pathways and defined contacts for specifically for non-specialised practices.

**Wien-spezifische
Faktoren größtenteils
deckungsgleich mit bereits
genannten Problemen**

**Verbesserungspotenzial:
mehr Zentren, kürzere
Wartezeiten und klarere
Überweisungspfade**

6 Results: Endometriosis Care: Guidelines Versus Clinical Practice in Vienna

Guideline recommendations synthesised in the synopsis were compared against survey data from Viennese doctors (n=49) and patients (n=53) across diagnosis, treatment, referral, care organisation, and patient-centred management. Only topics covered by guidelines and at least one survey were included; differences between perspectives were interpreted cautiously, as clinician and patient data reflect different constructs. Concordance was rated qualitatively in six categories, ranging from fully concordant to not assessable (see Chapter 3.6 for methods and category definitions)

**Abgleich von
Leitlinienempfehlungen &
Wiener Versorgungspraxis**

Diagnostic-work up

Table 6-1: Comparison of diagnostic procedures: guidelines vs. survey

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
TVUS as first-line imaging	All 5 guidelines recommend TVUS as the primary imaging modality	100% reported TVUS as a first-line investigation; 95.1% report using it "always" as part of the standard work-up	79.2% reported ultrasound as an initial investigation	Fully concordant Provider-reported practice closely reflects the clear and consistent guideline benchmark. Ultrasound was also the most frequently reported initial investigation among patients.
Biomarkers/serum CA-125	All 5 guidelines consistently advise against diagnostic use, because of insufficient sensitivity and specificity	26.5% use CA-125 as part of the diagnostic process	Blood tests reported by 22.6% as an initial investigation (test type not further specified).	Broadly discrepant Provider-reported use of biomarkers such as CA-125 was broadly discordant with guideline recommendations against their use for diagnosing endometriosis. However, the specific indication was not captured, and patient-reported blood testing could not confirm this practice.
Physical/gynaecological examination	Most guidelines include clinical examination in the diagnostic work-up	100% reported history-taking plus gynaecological/abdominal examination as standard practice	66.0% reported a physical or vaginal examination among their first investigations	Broadly concordant Provider-reported practice reflects the guideline direction. The lower patient-reported proportion may reflect recall or differences in terminology.
Negative imaging does not exclude the disease	Emphasised across guidelines, particularly for superficial disease, which remains poorly detected on imaging; ESHRE, NICE and HSE recommend continued referral or assessment even with normal imaging	Not directly queried among healthcare providers	22.6% report that further management was clearly discussed when initial investigations were unremarkable, yet symptoms persisted; 58.5% report it was not discussed.	Not assessable Guideline recommendation is clear and consistent, with consistent direction across the guidelines that address this point (ESHRE, NICE, HSE). Patient-reported data show that a defined next step after normal imaging was communicated in 22.6% of cases. Provider-side data on this specific point are not available.
MRI as second-line diagnostics	Consistently positioned as second-line for suspected DIE across AWMF, RANZCOG, NICE and HSE; HSE explicitly advises against MRI as a routine first-line test	MRI used predominantly for suspected DIE (65.2%) and unclear ultrasound findings (63.0%); no routine first-line use reported	15.1% reported MRI among the initial investigations; (multiple answer item)	Broadly concordant Provider-reported practice reflects the guideline positioning of MRI as a targeted rather than routine investigation. Patient reported data suggests relatively limited use during the initial work-up but does not permit assessment of its sequence or specific indication.

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Diagnostic laparoscopy	Positioned as an option when non-invasive work-up is inconclusive, not routine; consistent direction across guidelines.	No routine use reported; 38.8% reported that they never use it for diagnostic purposes. The most common indications were unclear findings after non-invasive work-up or confirmation of clinical suspicion (32.7% each).	17.0% reported laparoscopy as an initial investigation (multiple answer item)	Broadly concordant Full agreement between guidelines and HCP survey on selective, non-routine use; the patient survey (17.0% reporting initial use) suggests some uncertainty.
Clinical working diagnosis without laparoscopy	Not explicitly regulated: guidelines support non-invasive diagnosis but do not specify how binding a purely clinical or sonographic diagnosis may be.	69.4% reported routinely or frequently establishing a working diagnosis without laparoscopy.	Not directly assessed	Not assessable The absence of a sufficiently clear and consistent guideline benchmark precluded assessment of concordance
Classification systems (#Enzian, rASRM, AAGL)	Only AWMF provides detailed guidance (#Enzian, 2021); NICE and RANZCOG favour detailed descriptive documentation over formal staging	61.3% reported using a standardised classification system routinely or frequently in surgical cases; 20.4% consider it not applicable	—	Not assessable Guideline positions differ; variation in provider practice reflects differing guideline positions rather than clear discordance.
Time to diagnosis and diagnostic pathway structure	Timely recognition is stated as an aim across all guidelines; however, the organisational structures and processes required to achieve it are not clearly specified. Core symptoms are intended to trigger prompt further work-up	16.3% reported following a formally documented diagnostic protocol; 57.1% relied on an informal pathway and 22.4% had none. When asked about symptoms triggering suspicion of endometriosis, clinicians most frequently cited dysmenorrhoea, dyspareunia, dyschezia and pelvic pain, while less typical gastrointestinal, urinary, bleeding-related and extrapelvic symptoms were mentioned less often.	Mean time to diagnosis: 9.7 years; 77.4% consulted ≥3 providers before diagnosis. When initial work-up was unremarkable but symptoms persisted, 58.5% reported that further management had not been clearly discussed. Dysmenorrhoea, exhaustion and digestive problems were the most frequently cited symptoms prior diagnosis.	System level implementation gap* The prolonged diagnostic delay and limited use of formal diagnostic pathways contrasts with the guideline aim of timely recognition. However, the absence of an explicit pathway benchmark precluded assessment of concordance.

*Note: * Although no numerical threshold for timely diagnosis is specified in the guidelines, a mean delay of 9.7 years cannot reasonably be considered timely, which justifies classification as a system-level implementation gap despite the absence of a graded benchmark.*

Abbreviations: AAGL ... American Association of Gynaecologic Laparoscopists; AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; CA-125 ... Cancer Antigen 125; DIE ... Deep Infiltrating Endometriosis; ESHRE ... European Society of Human Reproduction and Embryology; HCP ... Healthcare Provider; HSE ... Health Service Executive; MRI ... Magnetic Resonance Imaging; NICE ... National Institute for Health and Care Excellence; rASRM ... revised American Society for Reproductive Medicine (classification); RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; TVUS ... Transvaginal Ultrasound

Diagnostic practice showed varying degrees of alignment with guideline recommendations across the areas examined. TVUS was consistently applied as first-line imaging, in line with all five guidelines, and physical/gynaecological examination was also broadly concordant with guideline recommendations, supported by both provider- and patient-reported findings.

In contrast, biomarkers such as CA-125 were reported as part of the typical diagnostic work-up by over a quarter of providers, which was broadly discordant with the consistent guideline recommendation against their use for diagnosing endometriosis. However, the survey did not capture the specific clinical context, including whether testing was limited to cases involving atypical or suspicious adnexal findings. MRI and diagnostic laparoscopy were both used selectively rather than routinely by providers, broadly matching their guideline positioning as second-line or optional tools for inconclusive cases. Patient reports also indicated relatively limited use of MRI and laparoscopy during the initial diagnostic work-up, although the survey did not establish their sequence or clinical indication. This interpretation was further supported by the finding

hohe Konkordanz bei zentralen diagnostischen Verfahren;
Ausnahme: CA 125

weiterführende Diagnostik überwiegend selektiv eingesetzt

Lücken im diagnostischen Pfad & verzögerte Diagnosestellung

that providers commonly established a working diagnosis without laparoscopy. However, concordance for this specific practice could not be assessed independently because the guidelines did not define a sufficiently explicit benchmark.

Alignment with the guideline principle that negative imaging does not exclude disease was not fully assessable. Just over a fifth of patients reported that further management had been clearly discussed when initial investigations were unremarkable despite persisting symptoms. As this issue was not directly assessed in the provider survey, the finding primarily reflects patients' experiences of communication and further management rather than provider practice as a whole. Practice relating to classification systems was more variable and could not be assessed against a clear and unified guideline standard. Time to diagnosis and diagnostic pathway structure were also assessed. Only a minority of providers reported following a formally documented pathway, while patients described prolonged diagnostic delays and consultation of multiple providers. Although clinicians most often identified the typical symptom complex as triggering investigation, fatigue and digestive symptoms were reported frequently by patients but appeared less prominent in provider responses, suggesting a potential gap in recognition of the broader symptom spectrum.

Therapy

Table 6-2: Comparison of therapy: guidelines vs. survey

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Progestogens as first-line therapy	All 5 guidelines recommend progestogens as a first-line hormonal option, with consistent direction.	53.1% selected progestogen monotherapy as first-line, making it the most common single option.	60.8% reported receiving hormonal therapy (pill, progestogen or GnRH) as first-line treatment.	Broadly Concordant Provider-reported practice reflects the clear and consistent guideline benchmark. Patient-reported data supports first-line hormonal treatment broadly but did not permit assessment of progestogen use specifically.
Combined hormonal contraceptives	Recommended as a first-line hormonal option by most guidelines, although positioning varied across guidelines	24.5% selected CHC as first-line treatment, making them the second most commonly reported option	Hormonal treatment was the most frequently reported first-line therapy (58.5%), although the survey did not distinguish CHCs from other hormonal options	Broadly Concordant Provider-reported first-line use broadly reflected guideline recommendations. Patient-reported data did not permit assessment of CHC use separately.
Analgesics/NSAIDs as basic therapy	All 5 guidelines recommend analgesics as part of pain management, without defining a uniform treatment sequence.	8.2% use analgesics alone as a first-line approach	19.6% reported receiving pain medication first-line; 88.7% had used it at some point over the disease course.	Broadly concordant Provider- and patient-reported use broadly reflected the guideline recommendation to include analgesics in pain management. However, differences in treatment timing and use alone or alongside other therapies limited direct comparison.
GnRH agonists/antagonists (second-line)	Generally recommended as second-line treatment; add-back therapy is consistently recommended. AWMF positions oral GnRH antagonists more prominently, including as a first-line option after surgical diagnosis.	4.1% select GnRH agonists/antagonists as first-line in the general symptomatic scenario surveyed.	Not separately assessed by drug class; 47.2% reported hormonal treatment as an additional therapy over the disease course.	Broadly Concordant Low provider-reported first-line use broadly reflected the second-line positioning in most guidelines. Patient-reported data did not permit assessment of GnRH use separately.

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Surgery as a first-line approach	Consistently presented as one option among several rather than routine first-line treatment, across all five guidelines.	0% selected surgery as first-line for symptomatic endometriosis without a wish to conceive.	9.4% received a surgical intervention as their initial treatment; 43.4% had undergone surgery at some point during the disease course.	Broadly Concordant Provider- and patient-reported findings support the limited use of surgery as initial treatment approach. It was reported as initial treatment by a small minority of patients, but the clinical indication was not captured and may have justified early surgical management in selected cases.
Indications for surgery	Persistent pain despite conservative treatment, suspected deep disease, ovarian endometrioma and fertility concerns are cited across guidelines as indications for surgery.	Persistent pain despite conservative treatment was the most frequently reported indication (75.5%), followed by suspected DIE (57.1%), ovarian endometrioma (53.1%) and infertility or wish to conceive (53.1%); lack of response to hormonal therapy was reported less often (14.3%).	Not assessed	Broadly Concordant Provider-reported indications correspond closely to those listed across the guidelines
Psychosocial assessment/sexual dysfunction screening	Guideline recommendations varied, ranging from screening for anxiety, depression and sexual dysfunction to broader recognition of psychosocial support needs.	Psychotherapy/psychology reported as a cooperation partner by 36.7% of providers; no systematic screening protocol reported.	Psychological health was the most frequently affected life domain overall (90.6%); 18.8% of patients reported receiving information on self-help resources	Not assessable The absence of a sufficiently clear and consistent guideline benchmark precluded assessment of concordance. Provider findings indicate referral-based support rather than systematic screening, while patient findings showed substantial psychological burden and limited information on support resources.
Non-pharmacological approaches (physiotherapy, psychological interventions, acupuncture, diet, TENS, osteopathy)	Addressed unevenly across guidelines; with AWMF providing the most detailed recommendations and other guidelines offering more limited specific guidance.	Pelvic floor physiotherapy and acupuncture were reported to be predominantly provided externally rather than in-house (27 vs 11, and 23 vs 8 respectively).	54.7% reported physiotherapy and 50.9% psychological support as additional therapies over the disease course; 2.0% received physiotherapy as initial treatment	Not assessable The absence of a sufficiently clear and consistent guideline benchmark precluded assessment of concordance. Both surveys indicated use of non-pharmacological approaches mainly as additional rather than first-line treatment, and predominantly provided externally

Abbreviations: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; CHC ... Combined Hormonal Contraceptives; DIE ... Deep Infiltrating Endometriosis; GnRH ... Gonadotropin-Releasing Hormone; TENS ... Transcutaneous Electrical Nerve Stimulation

Therapeutic management showed the strongest degree of alignment with guideline recommendations among the areas examined. Progestogen monotherapy was the most frequently selected first-line treatment among providers, while CHCs and analgesics were also used in accordance with their recommended roles in hormonal treatment and pain management. Patient-reported findings similarly supported the predominant use of hormonal therapy and analgesics, although the survey did not distinguish between individual hormonal drug classes. GnRH agonists and antagonists were rarely selected as first-line treatment, consistent with their recommendation as a second-line option in most guidelines.

Surgery was not selected as a first-line approach by providers and was reported as initial treatment by only a small minority of patients, broadly supporting guideline positioning as an option for selected cases rather than routine first-line management. The clinical indication for initial surgery in these patients was not captured and may have justified early surgical management in selected cases. The indications cited for surgery, persistent pain despite conservative treatment, suspected deep disease, ovarian endometrioma and fertility concern, also corresponded closely to those listed across guidelines.

hohe Konkordanz bei medikamentöser Therapie

**Operation
leitlinienkonform;
jedoch nicht als
routinemäßige
Erstlinientherapie**

Psychosocial assessment and non-pharmacological approaches could not be formally assessed for concordance, as the guidelines did not provide sufficiently clear or consistent benchmarks. For psychosocial care, providers reported cooperation with psychotherapy or psychology services rather than systematic screening, while patients reported psychological health as the most frequently affected life domain and experienced limited provision of information on self-help resources. For non-pharmacological approaches, physiotherapy and acupuncture were predominantly provided externally rather than in-house, and patients reported these approaches mainly as additional rather than first-line therapies.

Psychosoziale und nicht-medikamentöse Versorgung uneinheitlich verankert

Fertility

Table 6-3: Comparison of treatment for infertility: guidelines vs. survey

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Individualised (surgical) decision-making for fertility	ESHRE, RANZCOG and HSE emphasise individualised decisions considering age, ovarian reserve, infertility duration, pain, prior surgery and patient preference; ESHRE references the Endometriosis Fertility Index (EFI).	Preferred management strategy for patients with a wish to conceive: early referral to reproductive medicine (40.8%), case-dependent approach without a uniform protocol (22.4%), combined operative/reproductive strategy (18.4%), conservative-first (14.3%); no respondent favours primary surgery.	71.4% (20/28) reported that their wish to conceive was actively factored into treatment planning.	Broadly Concordant* Provider-reported strategies reflect the multi-factorial decision-making and individualised approach recommended across guidelines, and most patients reported that their wish to conceive had been considered in treatment planning.
Fertility counselling	AWMF provides the most explicit guidance, recommending counselling on reduced fertility, the effect of age, and oocyte/embryo cryopreservation.	Fertility-related counselling reported as always provided by 71.4% and mostly provided by a further 28.6%; No respondent reports rarely/never counselling.	Not assessed	Not assessable Providers reported frequent fertility counselling, but the survey assessed frequency rather than content. As detailed counselling requirements were specified only in some guidelines, concordance could not be assessed.

*Note: * This patient item assessed whether fertility wishes were considered, rather than the specific individualised criteria addressed; concordance was therefore assessed at a broader level.*

Abbreviations: AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; EFI ... Endometriosis Fertility Index; ESHRE ... European Society of Human Reproduction and Embryology; HSE ... Health Service Executive; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Provider-reported fertility management broadly reflected the individualised, multifactorial approach recommended across guidelines, and 71.4% of patients reported that their wish to conceive had been considered in treatment planning. All physicians reported providing fertility counselling always or most of the time; however, concordance regarding its content could not be assessed because the survey captured frequency rather than the specific information provided

weitgehende Konkordanz bei individualisiertem Fertilitätsmanagement

Adolescents

Table 6-4: Comparison of the treatment of adolescents: guidelines vs. survey

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Treatment and referral of adolescents to specialist care	Adolescent-specific recommendations are heterogeneous. Where addressed, guidelines favour conservative, age-appropriate management. RANZCOG and NICE explicitly recommend specialist referral.	55.1% of physicians report providing adapted treatment and/or referral for adolescent patients; 18.4% treat them no differently from adults; 14.3% do not treat adolescent patients at all.	Not assessed	Broadly concordant* Most providers reported adapted treatment and/or referral for adolescents, broadly aligning with the recommendations of the guidelines addressing adolescent care. However, guideline coverage was limited, and the survey did not clarify how adolescents were managed or referred when respondents did not provide care themselves.

*Note: *Assessment considered appropriate because both guidelines addressing adolescent care provided a sufficiently clear and consistent direction.*

Abbreviations: NICE ... National Institute for Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Adolescent-specific recommendations were heterogeneous but generally favoured conservative, age-appropriate management, with NICE and RANZCOG additionally recommending referral to specialist care. Provider practice broadly reflected this direction, with 55.1% reporting adapted treatment and/or referral. However, a substantial minority treated adolescents no differently from adults or did not treat adolescent patients themselves. However, 18.4% reported treating adolescents no differently from adults, while 14.3% did not treat adolescent patients themselves. For the latter group, the survey did not establish whether patients were referred to specialist care

Versorgung Jugendlicher grundsätzlich leitliniennah, jedoch unterschiedlich umgesetzt

Healthcare Organisation & Patient Experience

Table 6-5: Comparison of Healthcare organisation and Patient experience: guidelines vs. survey

Topic	Guideline recommendation and international benchmark	Clinical practice	Patients experience	Assessment and Interpretation
MDT	Guidelines and international frameworks broadly support multidisciplinary involvement, particularly for complex disease, but vary substantially in the recommended composition, indications, and degree of formalisation.	Structured MDT collaboration was reported by 30.6% of respondents, informal collaboration by 44.9%, and no collaboration by 20.4%. The disciplines involved varied considerably between practices	Not directly assessed; 28.3% report having been referred to a specialist centre, which is where more formal MDT structures are typically located	Not assessable The absence of a uniform benchmark for MDT structure limits formal concordance assessment. Although 75% of HCPs reported interdisciplinary collaboration, this was predominantly informal and inconsistently structured, suggesting potential limitations in the organisation of multidisciplinary care.
Centralisation of complex cases in specialist/certified centres	All guidelines support centralising complex disease in specialist centres, without defining formal certification criteria or expected service coverage International models vary, ranging from structured certification to regional designation or accreditation.	18.4% of gynaecologists were affiliated with a certified endometriosis centre; 79.6% reported no affiliation.	28.3% had been referred to a specialist centre; 69.8% had not. Diagnosis more often occurred in a non-specialised gynaecological practice (39.6%), than a certified centre (30.2%).	System-level implementation gap Both surveys suggest limited reach of certified specialist centres and referral pathways. This contrasts with the recommendations for centralisation of complex cases, although the surveys did not establish whether those who were referred required specialist care. In addition, the absence of defined coverage or referral targets limits assessment.
Structured referral pathways between care levels	RANZCOG, HSE, and AWMF specify referral criteria (treatment failure, severe/persistent symptoms, suspected disease, fertility concerns); NICE describes managed clinical networks without specific referral criteria. Internationally, referral is mandatory only in Denmark for complex cases; the HSE tiered model includes an explicit, structured, multi-level referral pathway	Unclear referral pathways were cited as a structural barrier by 27.3% of clinicians, and standardised referral pathways as an improvement priority by 25.0%.	83.0% reported periods in which they were unable to obtain help for their symptoms; recurring themes in free-text responses include symptom dismissal, diagnostic uncertainty, long waits and limited specialist availability.	Not assessable The surveys did not directly assess the existence or functioning of referral pathways. Moreover, guideline recommendations remain broad, and the explicit HSE tiered model is specific to the Irish healthcare system and cannot serve as a direct benchmark for Vienna. Formal concordance assessment was therefore not possible, although reported barriers suggest that referral between care levels may be insufficiently structured.

Abbreviations: MDT ... Multidisciplinary Team; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; HCP ... Healthcare Provider; HSE ... Health Service Executive; AWMF ... Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften; NICE ... National Institute for Health and Care Excellence

MDT involvement varied considerably: structured collaboration was reported by 30.6% of respondents, informal collaboration by 44.9%, and no collaboration by 20.4%, with disciplines differing between practices. Concordance could not be formally assessed due to the lack of a uniform benchmark. Overall, MDT involvement appeared to be present but was predominantly informal and inconsistently structured.

Structured referral pathways could not be formally assessed because their existence and functioning were not directly examined, and guideline recommendations remained broad. Unclear pathways were cited as a structural barrier for clinicians and as an improvement priority. Consistent with these provider-reported barriers, 83.0% of patients reported periods without access to help, with symptom dismissal, diagnostic uncertainty, long waits and limited specialist availability recurring as themes.

Centralisation of complex cases suggested a possible system-level implementation gap: only 18.4% of providers were affiliated with a certified endometriosis centre, and just 28.3% of patients had been referred to one, with diagnosis occurring more often in non-specialised practices than certified centres.

**Systemlücke
bei Zentralisierung
komplexer Fälle**

**organisatorische
Versorgungsstrukturen
(MDT, Überweisungspfade)
mangels uneinheitlicher
Leitlinienvorgaben nicht
beurteilbar**

Shared Decision-Making and Patient Information

Table 6-6: Comparison of shared decision-making and patient information: guidelines vs. survey

Topic	Guideline recommendation	Clinical practice	Patients experience	Assessment and Interpretation
Individualised, preference-sensitive treatment decisions	NICE, RANZCOG and HSE recommend individualised treatment decisions that consider patient preferences, side effects, efficacy, cost, availability, and reproductive intentions.	65.3% considered the time available sufficient for shared decision-making (mean 22 minutes; median 20; range 2-45).	47.2% agreed that they were fully or somewhat included in treatment decisions, while 28.3% somewhat or strongly disagreed.	System-level implementation gap Provider-reported conditions appear broadly supportive of shared decision making, but patient experiences indicate that this was not consistently achieved. Most providers reported having sufficient time for shared decision-making, whereas patient experiences were more variable. This pattern reflects partial and variable implementation rather than a uniform divergence from the guideline recommendation.
Information provision and counselling (breadth & quality) across the care pathway	NICE, RANZCOG and ESHRE recommend comprehensive, individualised information on diagnosis, treatment options, risks/side effects, fertility, follow-up, waiting times, costs, and psychosexual/psychosocial needs, including surgery-specific counselling where relevant	Not assessed	Information provision was uneven: most commonly informed about treatment options (41/53) and fertility implications (29/53); less commonly informed about side effects (16 vs. 37 not informed), self-help resources (10 vs. 43), and the chronic nature of the condition (25 vs. 28). Free-text responses also described gaps in communication around surgery and follow-up	System-level implementation gap Where guidelines specify a clear informational scope, patient-reported experience indicates uneven and incomplete coverage across the care pathway. Provider-side data on this point are not available.

Abbreviations: NICE ... National Institute for Health and Care Excellence; RANZCOG ... Royal Australian and New Zealand College of Obstetricians and Gynaecologists; HSE ... Health Service Executive; ESHRE ... European Society of Human Reproduction and Embryology

Individualised, preference-sensitive treatment decisions suggested a system-level implementation gap. Provider- and patient-reported findings differed: while most providers considered the available time sufficient for shared decision-making, fewer than half of patients felt fully or somewhat included in treatment decisions, and a notable proportion actively disagreed with this. This pattern points to partial and variable implementation rather than a uniform divergence from guideline recommendations on individualised, preference-sensitive

**gemeinsame
Entscheidungsfindung,
Information & Beratung
nur teilweise umgesetzt**

care. Information provision and counselling across the care pathway likewise indicated a partial system-level implementation gap, though provider-side data on this point were not available. Patient-reported experience indicated uneven coverage across topics: treatment options and fertility implications were most commonly addressed, while side effects, self-help resources and the chronic nature of the condition were less consistently covered. Free-text responses further pointed to gaps in communication around surgery and follow-up.

7 Discussion

7.1 Summary of Findings

Guideline Synopsis

This review synthesised recommendations from five international guidelines (ESHRE, RANZCOG, NICE, AWMF, HSE) on the diagnosis and management of endometriosis.

Methodologically, AGREE II appraisal showed consistently strong performance in Scope and Purpose, Stakeholder Involvement, and Clarity of Presentation, but weak and heterogeneous performance in Applicability and Editorial Independence, and no guideline met the threshold for high quality across all six domains. Four of five guidelines applied GRADE or a partial GRADE approach; AWMF, as an S2k consensus guideline, did not.

All guidelines emphasised that a normal examination or negative imaging does not exclude endometriosis, particularly superficial peritoneal disease, which remains poorly captured by any imaging modality. Across the five included guidelines, this point, together with transvaginal ultrasound as first-line imaging and hormonal treatment of endometriosis-associated pain with CHCs or progestogens, represented the strongest area of consensus, generally supported by stronger recommendation grades and moderate-certainty evidence. Laparoscopy was increasingly positioned as an option for inconclusive cases rather than a mandatory diagnostic step. GnRH agonists/antagonists and add-back therapy were positioned as second-line pain management options. Surgical treatment was uniformly mentioned as one option among several rather than a first-line approach, with cystectomy generally preferred over drainage or ablation for ovarian endometrioma and specialist-led resection recommended for DIE.

Greater heterogeneity and lower certainty of evidence were observed for the timing and role of surgery, fertility-preserving interventions, and management before assisted reproduction. For endometriosis-associated infertility specifically, guidelines consistently recommended against hormonal suppression to improve fertility and supported individualised, multi-factorial surgical decision-making, though the certainty of the underlying evidence was predominantly low. Nevertheless, all guidelines emphasised individualised treatment planning, consideration of reproductive goals and patient preferences, and access to multidisciplinary, patient-centred care. Recommendations on complementary therapies, asymptomatic disease, adolescent-specific care, psychosocial support, long-term follow-up, and classification systems were addressed unevenly and were generally less specific, more frequently based on expert consensus or descriptive documentation.

Organisation of Care and Delivery

Across the guidelines reviewed, endometriosis was consistently recognised as a chronic condition with substantial physical, psychological and social consequences, requiring coordinated, long-term and, where appropriate, multidisciplinary care. However, several structural aspects of care provision were often only loosely defined or not addressed explicitly. This applied in particular to referral pathways, the division of responsibilities across levels of care, certification standards, the composition of multidisciplinary teams, quality assurance mechanisms, professional training and structured follow-up.

Einschluss von 5 Leitlinien

AGREE II: Methodische Heterogenität, Schwächen v. a. bei Umsetzbarkeit

hohe Übereinstimmung bei Diagnostik und medikamentöser Therapie

heterogene Empfehlungen & geringere Evidenzsicherheit bei komplexeren Versorgungsfragen

gemeinsames Versorgungsverständnis, begrenzte Strukturvorgaben

This lack of clarity was reflected, and often amplified, in the wider literature, which showed considerable international variation in tiered care models, the designation of specialist centres, certification requirements and referral arrangements. In several health systems, complex cases continued to be managed outside designated specialist centres, pointing to a gap between guideline recommendations and actual clinical practice. The considerable burden of chronic disease was likewise only partly reflected in formal care and social support structures; Australia was the only country identified as having a national action plan for endometriosis.

Some frameworks nonetheless provided clearer structure. The HSE model, for instance, defined responsibilities and escalation criteria across primary, secondary, regional specialist and supra-regional care in comparatively explicit terms. Multidisciplinary involvement tended to be more formalised at higher levels of care, although team composition and access varied considerably between settings. Systematic auditing, mandatory registries, outcome monitoring and structured professional training, particularly in primary care, remained limited overall. Patient information and shared decision-making were not consistently embedded in care pathways, and structured rehabilitation, along with the evidence base supporting it, remained underdeveloped.

Empirical Findings

The Vienna-based patient survey (n=53) indicated a mean diagnostic delay of 9.7 years, with most respondents having consulted three or more providers before diagnosis. Endometriosis was most often diagnosed in non-specialised gynaecological practice, and only 28.3% of patients reported ever being referred to a certified centre. Hormonal therapy was the most frequently reported first-line treatment; surgical and non-pharmacological approaches were used considerably less often as an initial strategy. Patients described a high symptom burden prior to diagnosis, substantial psychosocial impact (90.6% reporting effects on psychological health), and near-universal experience of symptom dismissal by healthcare providers. Information and counselling were reported unevenly across the care pathway, with treatment options and fertility implications most commonly addressed, and side effects, self-help resources, and the chronic nature of the condition less consistently covered; free-text responses further described gaps in communication around surgery and follow-up. Satisfaction with current care was mixed, with psychosocial support and cost reimbursement rated poorest among six assessed domains, and 88.7% of respondents reporting out-of-pocket expenditure not covered by statutory insurance.

The provider survey (n=49) showed near-universal use of history-taking, pelvic examination, and transvaginal ultrasound when endometriosis was suspected. First-line treatment most commonly consisted of progestogen-only or combined hormonal therapy. Diagnostic laparoscopy was not used routinely; clinicians commonly established a working diagnosis without surgery and considered laparoscopy mainly when non-invasive findings remained inconclusive or diagnostic confirmation was sought. More than one-quarter of providers reported using CA-125 diagnostically. Only 16.3% of respondents reported following a formally documented diagnostic pathway, while individual clinical experience was cited more often than international guidelines as the basis for existing practice. Overall, 18.4% of providers were affiliated with a certified endometriosis centre, and structured interdisciplinary collaboration was reported by 30.6%. Most providers considered the time available for treatment decisions sufficient.

**Lücke zwischen
Versorgungsempfehlungen
& Praxis**

**Versorgungsstufen,
MDT-Strukturen &
Qualitätssicherung;**

**Patient:innen berichten
lange Diagnosewege,
hohe Belastung,
häufige Erfahrung mit
Symptomabwertung &
Versorgungslücken**

**leitliniennahe
Diagnostik & Therapie,
aber wenig strukturierte &
spezialisierte Versorgung**

Guideline – Practice Comparison

The comparison showed full or broad concordance for several core clinical practices, particularly first-line use of transvaginal ultrasound, hormonal treatment with progestogens or CHCs, and avoidance of surgery as routine first-line treatment. The clearest discordance concerned the continued diagnostic use of CA-125, despite a uniform recommendation against this practice across all five guidelines. However, the survey did not capture the specific clinical indication or context of use, and some reported testing may have related to the differential assessment of atypical adnexal findings rather than to the diagnosis of endometriosis itself.

Across many other domains, findings pointed more towards system-level implementation gaps rather than direct discordance with discrete recommendations. This applied particularly to timely diagnosis, referral to specialised care, multidisciplinary provision, shared decision-making, information and counselling, and continuity of care. In these areas, the guidelines generally expressed broad objectives but often provided limited operational detail or measurable standards. Several organisational topics could therefore not be assessed against a single, sufficiently specific benchmark. Overall, Viennese practice appeared most closely aligned with guidelines in well-defined clinical areas, while the largest gaps concerned access, coordination, and the organisation of care.

**überwiegend
hohe klinische
Übereinstimmung,
mit Abweichungen beim
Einsatz von CA-125**

**Systemlücken bei
Zugang & Koordination,
Bewertung jedoch durch
fehlende klare
Leitlinienempfehlungen
begrenzt**

7.2 Critical Reflection

The guideline synopsis provides a clearer benchmark for discrete clinical decisions than for the organisation and delivery of care. Recommendations on first-line imaging and hormonal treatment were generally specific, consistent and, in some areas, comparatively well supported by evidence. Guidance on referral pathways, multidisciplinary care, psychosocial support, continuity of care and diagnostic timeliness was broader, less detailed and less uniform. This variation does not necessarily indicate substantive disagreement, but may reflect differences in scope, grading systems and operational detail. Similarly, cross-guideline agreement should not automatically be equated with strong supporting evidence.

Although recommendation strength and evidence certainty were not formally included in the adherence classification, the findings should be interpreted alongside the guideline synopsis to give some indication of their relative importance. Concordance with recommendations that were both highly consistent across guidelines and comparatively well supported by evidence can be interpreted with greater confidence than concordance in areas where guidance was more heterogeneous or evidence less certain. Transvaginal ultrasound as first-line imaging is the clearest example. A similar, though less pronounced, pattern was observed for first-line hormonal treatment, although the patient survey did not distinguish CHC from other hormonal options, limiting direct comparison with provider-reported practice. The non-routine use of diagnostic laparoscopy was also broadly concordant with guideline recommendations.

The reported diagnostic use of serum CA-125 by more than one quarter of providers suggests incomplete implementation of a clear and consistent guideline position. However, the survey did not capture the specific clinical indication for or context of testing, and some use may have related to the differential assess-

**Grenzen der
Leitlinienvergleichbarkeit**

**transvaginaler
Ultraschall als Beispiel
hoher Übereinstimmung**

**Grenzen der Erfassung
von Therapieumsetzung**

**CA-125-Nutzung
als potenzielle
Leitlinienabweichung**

ment of atypical adnexal findings rather than to the diagnosis of endometriosis itself. The finding should therefore be interpreted as broad rather than unequivocal discordance.

Conversely, several of the findings, classified as system-level implementation gaps or not assessable, correspond to areas where guideline guidance itself is merely consensus-based, unevenly detailed, or not graded at all. These findings reflect broader structural and organisational shortcomings in care delivery rather than non-adherence to a specific, well-evidenced recommendation and gaps likely say less about non-adherence to a specific, well-evidenced recommendation and more about broader structural and organisational shortcomings in how care is delivered, which may be more amenable to systemic or policy-level intervention than to improved guideline adherence per se. The additional international literature supports this interpretation, indicating that these organisational challenges extend across healthcare systems. The 9.7-year mean diagnostic delay reported by patients illustrates this well. While diagnostic delay is well documented in the literature, no standardised definition or evidence-based threshold for a “timely” diagnosis has been established. A recent systematic review likewise identified substantial diagnostic delays and highlighted the need for standardised definitions, increased awareness and targeted diagnostic interventions [36]. Accordingly, this finding is better understood as a shared, unmet aim across the care system than as a departure from a specific evidence-based standard.

A further consideration is that the limited specificity of guideline recommendations in several complex areas of care may itself reflect the broader state of endometriosis research and policy attention. Endometriosis has historically been strongly associated with surgical diagnosis, although recent guidelines have shifted towards non-invasive diagnostic approaches [37]. More broadly, substantial research gaps remain despite the high prevalence and burden of the condition. Comparatively limited evidence on long-term care pathways, multidisciplinary management, referral structures, patient information, and health-system implementation may therefore contribute to the vagueness or heterogeneity of organisational recommendations. These limitations should not be interpreted solely as methodological weaknesses of individual guidelines but also reflect persistent uncertainties in the underlying evidence base on the treatment and organisation of endometriosis care. The additional literature, Leroy et al. 2025 [25], Fang et al. 2023 [34], and the HSE tiered-care model [35], similarly identifies system-level gaps in chronic-care recognition, national planning, professional training and quality monitoring.

These limitations should not be interpreted solely as methodological weaknesses of individual guidelines but may reflect persistent uncertainties in the underlying disease process, the diagnostic and therapeutic evidence base, and the organisation, implementation, and evaluation of endometriosis care. The additional literature, Leroy et al. 2025 [25], Fang et al. 2023 [34], and the HSE tiered-care model [35] also identifies wide system-level gaps in chronic-care recognition, national planning, professional training, and quality monitoring.

The comparatively weak performance of all five guidelines in the AGREE II Applicability domain is particularly relevant. This domain addresses implementation barriers, resource implications and monitoring or audit criteria, areas in which the guidelines generally provided limited detail. Although providers rated the guidelines favourably, only 16.3% reported following a formally documented pathway, with practice more commonly based on individual clinical experience. These findings suggest that the gap between guideline aware-

**Diagnoseverzögerung
als Systemproblem**

**strukturelle
Versorgungslücken
bei begrenzten
Benchmarks**

**Grenzen der
Leitlinienempfehlungen
bei komplexen
Versorgungsfragen**

**Forschungs- &
Implementierungslücken**

**fehlende
Umsetzungshilfen in
Leitlinien erschweren
die Etablierung
standardisierter
Versorgungspfade**

ness and structured implementation may arise partly upstream of individual clinical practice. Guidelines that provide clear clinical recommendations but limited operational guidance may be difficult to translate into standardised local pathways. Variation in organisational practice may therefore reflect both incomplete local implementation and limitations in the operational usefulness of the guideline benchmark.

The patient and provider surveys offered complementary perspectives on care. Providers described their usual practice, available structures and perceived conditions of care delivery, whereas patients reported their experiences across diagnosis, treatment and follow-up. Differences between these perspectives are therefore informative rather than necessarily contradictory. For example, most providers considered the time available for shared decision-making sufficient, while patients reported substantially more variable involvement in treatment decisions. Similarly, although many providers re-reported referring complex cases and collaborating across disciplines, only a minority of patients had been referred to a certified centre, and many de-scribed difficulties obtaining appropriate help. This discrepancy suggests limited reach of certified specialist structures in practice; however, the surveys did not establish whether complex cases specifically were referred, and the absence of defined coverage or referral targets in the guidelines limits assessment of the extent of this gap. Information provision showed a comparable pattern: providers reported routinely addressing fertility and treatment decisions, while patients identified gaps in information on side effects, fertility, follow-up and available support.

A related discrepancy was observed between the symptoms clinicians most commonly identified as triggers for endometriosis investigation and those frequently reported by patients before diagnosis, particularly fatigue and digestive symptoms. However, the provider and patient two surveys assessed symptoms from different perspectives and were not linked at the level of individual clinical encounters, this comparison should be interpreted cautiously limiting direct comparison. This mismatch may contribute to delayed recognition and is consistent with the broader pattern of diagnostic de-lay discussed above: if clinically prompted investigation is anchored to a narrower symptom profile than patients actually experience, this may extend the interval before endometriosis is considered as a diagnostic possibility. This points towards a system-level implementation gap in timely recognition, although the absence of explicit organisational or temporal benchmarks limits more precise assessment. Overall, this points towards a system-level implementation gap in achieving the guideline aim of timely recognition, although the absence of explicit organisational and temporal benchmarks limits a more precise assessment. These findings suggest that the reported availability of favourable conditions does not necessarily translate into their consistent realisation in patient care.

Taken together, the surveys show that concordance with guidelines in selected clinical practices can coexist with substantial shortcomings in access, coordination, continuity, psychosocial support and affordability. The findings should therefore not be reduced to an assessment of whether individual providers follow specific recommendations but rather highlight a distinction between the quality of individual clinical decisions and the performance of the wider care pathway. Direct clinical practice, particularly first-line diagnostic and therapeutic decisions, showed a considerable degree of concordance with guideline recommendations, and this should be acknowledged alongside the shortcomings discussed above. By contrast, the more complex organisational dimensions of care, access to specialised services, coordination, continuity and psychosocial support, showed more consistent room for improvement.

Patient:innen- & Anbieter:innenperspektiven zeigen Lücken zwischen Anspruch & Realität der Versorgung

breiteres Symptomprofil der Patient:innen versus klinische Erkennungsmuster

Praxis trotz Defiziten in Zugang & Versorgungskontinuität

Verbesserungsbedarf in der Versorgungsorganisation trotz vorhandener Expertise

It is worth noting two further findings that qualify an unrelievedly negative interpretation of these organisational gaps. First, a subset of patients explicitly identified aspects of care that were already working well, particularly specialised clinical expertise and the role of patient-led support structures; the concerns raised should therefore indicate be read as indicating substantial room for improvement within an existing base of competent care, rather than as uniformly negative experiences across all care settings. Second, background research conducted for this report identified that a specialised inpatient rehabilitation centre for endometriosis has been established in Austria since the AWMF guideline noted the absence of such structures. This provides a concrete example of dedicated care infrastructure beginning to develop, although coverage and cost reimbursement remain limited, a small but concrete indication that dedicated care infrastructure in this area, while still limited in coverage and cost reimbursement, is beginning to develop. The cross-sectional design of this project cannot systematically capture such developments, but their existence is a relevant caveat to the otherwise static picture presented by the survey data.

More broadly, the value of the mixed-methods design lies in triangulating this ability to triangulate the guideline synopsis with local empirical data. This helps distinguish between findings that represent departures from clear recommendations, such as diagnostic CA-125 use, and those occurring in areas where the guidelines themselves provide limited or heterogeneous benchmarks, such as referral structures, MDT composition and diagnostic timeliness, synopsis with local empirical data: it allows a distinction between gaps that reflect genuine departures from clear, well-evidenced practice (e.g. CA-125) and gaps that instead reflect unresolved heterogeneity, limited evidence, or poor implementability within the guidelines themselves (e.g. referral structures, MDT composition, diagnostic timeliness), a distinction that a guideline summary or a stand-alone local survey could not offer on its own.

The findings suggest that improving endometriosis care in Vienna requires action at both clinical and system levels. In areas with clear and consistent recommendations, the focus is on supporting implementation of established practice. The larger challenges concern access, referral, coordination, multi-disciplinary care, psychosocial support and continuity, which are unlikely to be addressed through guideline dissemination alone. Across the guideline synopsis, international literature and local survey findings, the need for a more structured care pathway emerges as a central implication. Rather than creating a new organisational structure, this could build on existing services through clearer responsibilities, referral and escalation criteria, and defined points of contact across levels of care. Because international guidelines provide limited operational detail for several organisational aspects, local standards and quality indicators may be needed to support implementation and monitor whether changes improve patient experience and timely, equitable access to care.

Bestehende Stärken und zunehmende spezialisierte Versorgungsstrukturen

Aufbau spezialisierter Rehabilitationsstrukturen trotz begrenzter Versorgung

Mixed-Methods-Ansatz als Grundlage einer differenzierten Versorgungsbewertung

Verbesserungsbedarf auf klinischer & systemischer Ebene; strukturierter Versorgungspfad als zentrale Implikation

7.3 Limitations

Limitations of the Evidence Base

The included guidelines differ substantially in scope, terminology, and methodology used to grade evidence. Four guidelines applied GRADE or a comparable approach, whereas the AWMF S2k guideline was developed through structured consensus and did not assign formal certainty ratings. Cross-guideline comparison of recommendation strength is therefore limited; apparent differences may reflect variations in terminology rather than substantive disagreement, and apparent alignment may obscure differences in the underlying evidence base.

**unterschiedliche
Evidenzbewertung
begrenzt die
Vergleichbarkeit**

The AGREE II appraisal identified consistently poor performance across all five guidelines in two domains: Applicability and Editorial Independence. Applicability scores reflected limited guidance on implementation requirements, resource implications, and monitoring or audit criteria. Low scores for Editorial Independence may partly reflect incomplete reporting of funding sources and conflicts of interest rather than substantive bias, although the latter cannot be excluded. No guideline achieved high scores across all six domains. Thresholds distinguishing “high”, “moderate”, and “low” quality were defined by the review team, as AGREE II provides no official cut-offs; alternative thresholds may have resulted in different classifications.

**AGREE-II-Bewertung zeigt
Defizite bei Umsetzung &
Unabhängigkeit**

The guideline search was restricted to the Guidelines International Network, TRIP, and Google Scholar, without a full systematic database search or independent dual screening. Eligibility was also limited to publications in English or German, and to selected Western countries with comparable healthcare systems. Although this approach was considered sufficient to identify the major international guidelines relevant to the review, it may have excluded relevant guidance from other language regions or lower-income settings. However, this reflects a deliberate methodological choice rather than an oversight, as the inclusion criteria were explicitly restricted to this group of countries. The evidence base therefore reflects a small group of high-income, structurally similar healthcare systems rather than a global perspective. Several guidelines are under active revision (RANZCOG as a living guideline; AWMF and HSE with scheduled updates through 2028-2030); this synopsis therefore represents the guideline landscape at a specific point in time.

**eingeschränkte
Suchstrategie & zeitliche
Momentaufnahme der
Leitlinienlage**

The evidence underlying many recommendations remains limited. For several diagnostic and treatment questions, particularly those relating to fertility and second-line treatment, the certainty of evidence is consistently rated low or very low and is frequently based on observational studies or expert opinion rather than randomised trials. Heterogeneity in outcome definitions, pain measures and follow-up periods further limits comparison across studies. Consequently, even some strong recommendations were supported by only low- to moderate-certainty evidence, which should be considered when interpreting their transferability and the confidence placed in the findings.

**begrenzte Evidenzbasis
schränkt Sicherheit &
Übertragbarkeit von
Empfehlungen ein**

The analysis of international approaches to care organisation in Chapter 4.3 was based on a limited number of supplementary sources rather than a systematic review of care organisation models. Leroy et al. provide a policy comparison across five countries but do not report outcome data, and limited comparability between countries [27]. Fang et al. is based on a small and heterogeneous evidence base, with variable outcome measures and limited generalisability [36]. The international reference framework used to interpret the Viennese findings on care organisation is therefore relatively narrow and is itself subject to important limitations. In addition, models such as the HSE framework [37] were developed within different healthcare and governance structures and cannot be assumed to be directly transferable to Austria.

**begrenzte Evidenz
& Übertragbarkeit
internationaler
Versorgungsmodelle**

Limitations of this Review

Because the included guidelines differed substantially in scope, structure and evidence base, it was not possible to provide a fully conclusive answer to RQ1. Recommendations were therefore synthesised narratively and grouped by topic, with particular emphasis on areas of clear and consistent cross-guideline agreement. This approach was appropriate to the exploratory nature of the research question but inevitably reduced some guideline-specific detail and nuance.

**Vergleichbarkeit
durch unterschiedliche
Leitlinienstrukturen
eingeschränkt**

The empirical component of this project was designed as an exploratory, cross-sectional assessment and is subject to the limitations inherent in such assessments. With 53 completed patient questionnaires and 49 completed provider questionnaires over approximately three months, the sample sizes do not support population-level, representative conclusions; rather, the surveys provide an initial description of selected aspects of endometriosis care in Vienna. No formal sample-size or power calculation was undertaken, and both surveys experienced considerable drop-off between the start and finish, so non-response bias beyond the selection issues discussed below cannot be ruled out. Analyses were descriptive and limited to frequencies and percentages. No formal statistical testing of subgroup differences, such as comparisons between private and contracted providers or between centre-affiliated and non-affiliated providers, was undertaken, as this was not the objective of the survey and the necessary subgroup-specific data were not systematically collected. The observed variation therefore cannot be attributed to particular provider or organisational characteristics with statistical confidence.

**keine repräsentativen
Aussagen aus der
Querschnitterhebung
möglich**

Patients were recruited primarily through self-help groups, patient organisations, and online platforms, because direct access to eligible patients was not available and it could not be verified whether contacted gynaecologists distributed the survey. This recruitment strategy may have preferentially reached patients who were already engaged with patient advocacy and who were reasonably health-literate and digitally connected. This is consistent with the sample profile, in which approximately two-thirds held a university or applied-sciences degree, and only around a quarter reported a migration background. Although the questionnaire was made available in four additional languages to reduce access barriers, recruitment continued to rely largely on channels reaching a relatively homogeneous population, so it remains unclear how much the translations actually helped; patients with lower educational attainment, lower digital access, or weaker links to patient organisations may therefore be under-represented. In addition, patients who were not currently receiving care in Vienna were excluded. This may have omitted individuals who had discontinued care in Vienna or sought treatment elsewhere, including some with particularly negative care experiences.

**selektiver Zugang zu
Patient:innen über digitale
& organisierte Strukturen**

**mögliche
Unterrepräsentation
schwer erreichbarer
Patientengruppen**

The provider survey achieved a relatively low response rate compared with the number of providers contacted, with 49 completed questionnaires from more than 370 gynaecologists contacted, even after a reminder sent about six weeks later. Workload and survey fatigue may have contributed to this response pattern; however, providers with a particular interest or expertise in endometriosis may also have been more likely to participate, which would tend to inflate the reported levels of guideline awareness and structured practice compared with the average Viennese gynaecologist. The survey was restricted to gynaecologists and did not include physiotherapists, psychologists, pain specialists, specialist nurses, or other professionals whom both guidelines and patients identify as important contributors to multidisciplinary and psychosocial care. It therefore provides only a partial view of the wider care pathway.

The two surveys were conducted independently and are not linked at the level of individual patients and their actual providers. Differences between patient- and provider-reported findings, for example regarding fertility counselling or time for shared decision-making, therefore, represent contrasting aggregate perspectives rather than direct contradictions relating to the same care episode. The cross-sectional design also precludes causal or longitudinal conclusions: it cannot indicate whether outcomes such as diagnostic delay are improving over time, or what effect newer developments, such as the specialised rehabilitation centre mentioned in the background chapter, might be having. Retrospectively reported patient data, including time to diagnosis, number of providers consulted, and out-of-pocket expenditure, are subject to recall bias. Providers' self-reports of their own practice may have been shaped by social desirability, particularly regarding guideline adherence and time spent on shared decision-making, although anonymous participation was intended to reduce this bias.

Finally, the concordance assessment for RQ3 was qualitative rather than statistical. No fixed percentage thresholds were applied; classification into one of the six categories depended on the authors' interpretation of the direction, consistency, and specificity of the underlying guideline position, and another team working with the same data may have classified some points differently. Recommendation strength and evidence certainty were not formally incorporated into the assessment. Formally weighting deviations, for example, treating a departure from a strong, high-certainty recommendation as more consequential than a departure from a GPP or consensus statement, would have required a separate, pre-specified methodology and considerably more granular analysis than the scope of this report allowed. Moreover, the five guidelines used non-equivalent grading systems, making it difficult to construct a single defensible weighting scheme without introducing additional arbitrary assumptions. A structured framework explicitly linking concordance assessment to recommendation strength, evidence certainty, and guideline-level implementability would therefore be a valuable direction for future work building on this synopsis.

As noted above, adherence was classified according to the direction, consistency, and specificity of the guideline position rather than according to recommendation strength or evidence certainty, since a defensible weighting scheme across five non-equivalent grading systems was beyond the scope of this report. As illustrated in Section 4.2 by the findings on transvaginal ultrasound and serum CA-125, the concordance assessment should therefore be interpreted alongside the guideline synopsis in Chapter 5, which allows for some qualitative differentiation in the relative importance of individual findings.

Lastly, the empirical findings are specific to Vienna and cannot be generalised to other parts of Austria. Access to specialist services, referral distances, and provider density may differ substantially, particularly in rural areas.

geringe Rücklaufquote & eingeschränkte Abbildung der Versorgungspraxis

begrenzte Vergleichbarkeit & Verzerrungsrisiken der Survey-Daten

interpretationsabhängige Bewertung der Leitlinienübereinstimmung

Herausforderung der Gewichtung von Evidenz & Empfehlungstärke

Interpretation der Leitlinienübereinstimmung unter Berücksichtigung von Evidenz & Empfehlungskontext

begrenzte Übertragbarkeit

8 Conclusio and Action Points

This report synthesised recommendations of five international guidelines on the diagnosis and management of endometriosis, reviewed additional international literature on the organisation and delivery of care, and compared their recommendations with findings from patient and healthcare provider surveys conducted in Vienna. Overall, the evidence base for endometriosis care remains limited, with many recommendations relying on low-certainty evidence or expert consensus. Several core clinical recommendations were comparatively consistent and better supported across guidelines, particularly first-line transvaginal ultrasound, avoidance of CA-125 for diagnosis, hormonal treatment for pain, and positioning surgery as one option among several rather than routine first-line treatment. By contrast, recommendations on organisational aspects of care showed greater variation and generally provided less practical guidance on implementation.

Survey findings were broadly concordant with guideline recommendations in these more clearly defined clinical areas, while larger gaps emerged in referral, coordination, multidisciplinary care, follow-up and continuity. These findings suggest that the main areas for improvement lie in the organisation and coordination of care, which also varied considerably across the international models reviewed.

Policy Implications

Thus, adherence to clinical guidance alone is insufficient to ensure timely, coordinated, specialist, and patient-centred care. In areas with clear, consistent guideline recommendations, the priority lies in supporting consistent uptake through greater guideline awareness and continuing education. The larger gaps concern access, referral, coordination, multidisciplinary care, psychosocial support, and continuity of care, and are unlikely to be addressed through guideline dissemination alone. The survey findings reinforce these priorities, with providers particularly emphasising clearer referral pathways for non-specialist practice, improved training, and greater specialist and multidisciplinary capacity, while patients identified gaps in information, continuity and access to specialised care.

A central policy consideration is therefore the development of a common, systematically implemented care pathway for people with suspected or confirmed endometriosis in Vienna, so that access to assessment, information, follow-up, and specialist care does not depend on where a patient first enters the system. International models such as the HSE framework illustrate how clearer roles across primary care, general gynaecology and specialist services, together with defined escalation criteria based on symptom severity, treatment response and disease complexity, can support more coordinated care. Given the complexity and fragmentation of the Austrian health system, an entirely new organisational structure would be difficult to achieve in practice; a more feasible approach is an agreed framework across existing services, with priorities including:

- clearer standardised local referral and escalation pathways across statutory and private care, with defined responsibilities across levels of care;
- strengthened endometriosis education and training across the professional pathway, from undergraduate education through specialist training and continuing professional development

Synthese internationaler Leitlinien und Abgleich mit Wiener Versorgungspraxis

Begrenzte Evidenzbasis und uneinheitliche Empfehlungen zur Versorgung

Versorgungslücken vor allem bei Koordination und Kontinuität

Verbesserungsbedarf bei Zugang, Koordination und Patientenzentrierung

Entwicklung eines einheitlichen, abgestuften Versorgungspfads

Maßnahmen: Überweisungspfade, Fortbildung, ...

- consideration of a greater role for primary care in early recognition and management of uncomplicated symptoms;
- structured interdisciplinary collaboration with clearly defined roles and responsibilities across relevant professions and services;
- adequate specialist and multidisciplinary capacity to ensure timely access to appropriate care
- better integration of psychosocial and supportive care, including psychological support and other relevant allied health services, across the care pathway;
- integration of existing specialised services, such as the recently established rehabilitation centre for endometriosis in Austria;
- consistent provision of standardised patient information at key points in the care pathway, including treatment options, fertility, follow-up and available specialist and support services;
- locally developed standards and quality indicators, given the limited operational detail in international guidelines;
- monitoring whether these measures translate into better patient experience and more timely, equitable access to care.

Beyond healthcare organisation, the wider social consequences of endometriosis should also be reflected in care planning, recognising it as a chronic condition with potential effects on psychological well-being, work, education and family life. In Europe, Denmark provides an example of this broader approach, with a confirmed diagnosis linked to certain employment-related and financial support measures.

Finally, substantial evidence gaps remain across endometriosis care, both in clinical management and in the organisation and delivery of services and strengthening the evidence base should remain an international research priority. For Vienna, the more immediate priority is to translate existing evidence and guidance into a coordinated local care pathway with clear responsibilities, referral criteria and access to specialist and multidisciplinary care.

**... Primärversorgung,
Vernetzung,
Kapazitäten und
Patient:inneninformation**

**Berücksichtigung sozialer
und beruflicher Folgen von
Endometriose**

**Forschungsbedarf und
Umsetzung bestehender
Evidenz in
Versorgungspfade**

9 Literatur

- [1] Renner S. P. and Müller A. Endometriose. In: Strowitzki T. and Ortmann O., editors. *Klinische Endokrinologie für Frauenärzte*. Berlin, Heidelberg: Springer Berlin Heidelberg; 2024. p. 533-552.
- [2] Rajesh S., Mehmeti A., Smith-Walker T. and Kendall B. Diagnosis and management of endometriosis: summary of updated NICE guidance. *BMJ*. 2025;388:q2782. DOI: 10.1136/bmj.q2782.
- [3] Endometriose. [updated 29.02.2024]. Available from: <https://www.gesundheit.gv.at/krankheiten/sexualorgane/weibliche-sexualorgane/endometriose.html#wie-erfolgt-die-behandlung-einer-endometriose>.
- [4] Lamceva J., Uljanovs R. and Strumfa I. The Main Theories on the Pathogenesis of Endometriosis. *Int J Mol Sci*. 2023;24(5). Epub 20230221. DOI: 10.3390/ijms24054254.
- [5] Küpker W., Aizpurua J., Felberbaum R. E. and Diedrich K. Endometriose und Infertilität. *Die Gynäkologie*. 2024;57(3):131-137. DOI: 10.1007/s00129-024-05203-3.
- [6] Bayrak S., Allak A., Neugebauer T., Pardon S., Yilmaz-Aslan Y., Schiermeier S., et al. Barriers and Facilitators Affecting the Care of Patients with Endometriosis: A Scoping Review. *Geburtshilfe Frauenheilkd*. 2026;86(2):189-200. Epub 20260211. DOI: 10.1055/a-2765-4322.
- [7] Smolarz B., Szyłło K. and Romanowicz H. Endometriosis: Epidemiology, Classification, Pathogenesis, Treatment and Genetics (Review of Literature). *Int J Mol Sci*. 2021;22(19). Epub 20210929. DOI: 10.3390/ijms221910554.
- [8] Brauer L., de Cruppé W. and Geraedts M. “Take me seriously”: A qualitative interview study exploring healthcare experiences of endometriosis patients. *PLOS ONE*. 2025;20(5):e0323883. DOI: 10.1371/journal.pone.0323883.
- [9] Harder C., Velho R. V., Brandes I., Sehoul J. and Mechsner S. Assessing the true prevalence of endometriosis: A narrative review of literature data. *International Journal of Gynecology & Obstetrics*. 2024;167(3):883-900. DOI: <https://doi.org/10.1002/ijgo.15756>.
- [10] Gaiswinkler S., Wahl A., Antony D., Ofner T., Delcour J., Antosik J., et al. Menstruationsgesundheitsbericht 2024. Wien: Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz (BMSGPK), 2024.
- [11] Lee S. Y., Koo Y. J. and Lee D. H. Classification of endometriosis. *Yeungnam Univ J Med*. 2021;38(1):10-18. Epub 20200807. DOI: 10.12701/yujm.2020.00444.
- [12] International Working Group of AAGL E., ESHRE, WES, Tomassetti C., Johnson N. P., Petrozza J., Abrao M. S., et al. An international terminology for endometriosis, 2021†. *Human Reproduction Open*. 2021;2021(4). DOI: 10.1093/hropen/hoab029.
- [13] Horne A. W. and Missmer S. A. Pathophysiology, diagnosis, and management of endometriosis. *BMJ*. 2022;379:e070750. DOI: 10.1136/bmj-2022-070750.
- [14] Information zum Thema Endometriose. Patientenbroschüre basierend auf der ESHRE-Leitlinie zur Endometriose: ESHRE European Society of Human Reproduction and Embryology.
- [15] Brown J. and Farquhar C. Endometriosis: an overview of Cochrane Reviews. *Cochrane Database of Systematic Reviews*. 2014(3). DOI: 10.1002/14651858.CD009590.pub2.
- [16] Mazur-Bialy A., Tim S., Pepek A., Skotniczna K. and Naprawa G. Holistic Approaches in Endometriosis – as an Effective Method of Supporting Traditional Treatment: A Systematic Search and Narrative Review. *Reproductive Sciences*. 2024;31(11):3257-3274. DOI: 10.1007/s43032-024-01660-2.
- [17] Becker C. M., Bokor A., Heikinheimo O., Horne A., Jansen F., Kiesel L., et al. ESHRE guideline: endometriosis†. *Human Reproduction Open*. 2022;2022(2):hoac009. DOI: 10.1093/hropen/hoac009.
- [18] Xie M., Qing X., Huang H., Zhang L., Tu Q., Guo H., et al. The effectiveness and safety of physical activity and exercise on women with endometriosis: A systematic review and meta-analysis. *PLOS ONE*. 2025;20(2):e0317820. Epub 20250213. DOI: 10.1371/journal.pone.0317820.

- [19] Simoens S., Hummelshoj L., Dunselman G., Brandes I., Dirksen C., D’Hooghe T., et al. Endometriosis Cost Assessment (the EndoCost Study): A Cost-of-Illness Study Protocol. *Gynecologic and Obstetric Investigation*. 2010;71(3):170-176. DOI: 10.1159/000316055.
- [20] Weil Warten keine Option ist: WIGEV bietet Hilfe bei Endometriose. 23. September 2025 [cited 04.02.2026]. Available from: <https://gesundheitsverbund.at/weil-warten-keine-option-ist-wigev-bietet-hilfe-bei-endometriose/>.
- [21] Gaiswinkler S., Antony D., Delcour J., Pfabigan J., Pichler M. and Wahl A. *Frauengesundheitsbericht 2022*. Wien: Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz (BMSGPK), 2023.
- [22] *Frauengesundheit B. f. F. u. G. W. P. f. Endometriose: Was braucht es für eine adäquate Versorgung? Handlungsempfehlungen für Politik und Praxis*. Wien: Büro für Frauengesundheit und Gesundheitsziele/ Wiener Programm für Frauengesundheit, 2024.
- [23] Bachner F., Bobek J., Habimana K., Ladurner J., Lepuschütz L., Ostermann H., et al. *Austria: Health System Review*. Brussels: European Observatory on Health Systems and Policies, 2023 [cited 06.08.2026]. Available from: <https://eurohealthobservatory.who.int/publications/i/austria-health-system-review-2018>.
- [24] Österreichische Gesundheitskasse. *Hormonelle Behandlung von Endometriose als Kassenleistung*. 2022 (28.12.2022). [cited 23.09.2026]. Available from: <https://www.gesundheitskasse.at/cdscontent/load?contentid=10008.790065&version=1726206677>.
- [25] (OEGGG) Ö. G. f. G. u. G. Aus- & Weiterbildung [cited 07.05.2026]. Available from: <https://oeggg.at/junge-gyn/aus-und-weiterbildung/>.
- [26] EuroEndoCert. *Zertifizierte Kliniken und Praxen*. [cited 19.02.2026]. Available from: <https://www.euroendocert.de/de/zertifizierte-zentren/>.
- [27] Leroy R., Abbott J., Benahmed N., Camberlin C., De Jaeger M., Hartwell D., et al. Comparative analysis of the organization of endometriosis care in five high-income countries: implications for health systems and policy. *Human Reproduction*. 2025;40(12):2295-2309. DOI: 10.1093/humrep/deaf190.
- [28] Consortium A. N. S. *The AGREE II Instrument: User’s Manual and 23-item Instrument (2009 Update 2017)*. Hamilton, ON, Canada: AGREE Research Trust, 2017 [cited 27.07.2026]. Available from: <https://www.agreetrust.org/wp-content/uploads/2017/12/AGREE-II-Users-Manual-and-23-item-Instrument-2009-Update-2017.pdf>.
- [29] Tong A S. P., Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007; Volume 19: Number 6: pp. 349-357.
- [30] Mayring P. and Fenzl T. *Qualitative Inhaltsanalyse*. In: Baur N. and Blasius J., editors. *Handbuch Methoden der empirischen Sozialforschung*. Wiesbaden: Springer Fachmedien Wiesbaden; 2022. p. 691-706.
- [31] Group E. E. G. D. *Endometriosis Guideline of European Society of Human Reproduction European Society of Human Reproduction and Embryology (ESHRE)*, 2022 [cited 07.05.2026]. Available from: <https://www.eshre.eu/guideline/endometriosis>.
- [32]) T. R. A. a. N. Z. C. o. O. a. G. R. *Australian Living Evidence Guideline: Endometriosis*. RANZCOG, 2025 [cited 07.05.2026]. Available from: <https://ranzco.org.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf>.
- [33] (NICE) N. I. f. H. a. C. E. *Endometriosis: diagnosis and management*. London 2017 [cited 07.05.2026]. Available from: <https://www.nice.org.uk/guidance/ng73>.
- [34] (DGGG) D. G. f. G. u. G., (OEGGG) Ö. G. f. G. u. G. and (SGGG) S. G. f. G. u. G. *Diagnostik und Therapie der Endometriose*. [cited 07.05.2026]. Available from: https://register.awmf.org/assets/guidelines/015-045I_S2k_Diagnostik_Therapie_Endometriose_2025-10.pdf.
- [35] DeMaio A., McTiernan, A., Durand O’Connor, A., Reidy, F., O’Neill, A. *National Clinical Practice Guideline: Assessment and Management of Endometriosis*. National Women and Infants Health Programme and Institute of Obstetricians and Gynaecologists (IOG) 2025 [cited 07.05.2026].

- [36] Fang Q. Y., Campbell N., Mooney S. S., Holdsworth-Carson S. J. and Tyson K. Evidence for the role of multidisciplinary team care in people with pelvic pain and endometriosis: A systematic review. *Aust N Z J Obstet Gynaecol.* 2024;64(3):181-192. Epub 20230927. DOI: 10.1111/ajo.13755.
- [37] A National Framework for the Management of Endometriosis in Ireland. Dublin, Ireland: Health Service Executive, 2025 [cited 28.07.2026]. Available from: https://about.hse.ie/api/v2/download-file/file_based_publications/Endometriosis_Framework_73412.pdf/.
- [38] Kur für Frauen mit Endometriose. Available from: <https://www.moorbad-badgrosspertholz.at/endometriose-kur-in-oesterreich-moorbad-bad-grossertholz/>.
- [39] Telles-Correia D., Saraiva S. and Gonçalves J. Mental Disorder – The Need for an Accurate Definition. *Frontiers in Psychiatry.* 2018;9. DOI: 10.3389/fpsy.2018.00064.

Appendix

A-I Strength of Recommendation

ESHRE [31]:

Recommendations are classified as either ‘strong’ or ‘weak’ according to the GRADE approach, based on evidence, acceptability, costs, and the balance of benefits and harms. Additionally, Good Practice Points (GPPs) draw on the expertise of the guideline group to offer guidance on patient involvement, the management of specific procedures, and potential risks where direct evidence is lacking.

Table A-1: Strength of recommendation ESHRE

	Strong Recommendation	Weak Recommendation
Patients	Most people in your situation would want the recommended course of action, and only a small proportion would not	The majority of people in your situation would want the recommended course of action but many would not
Clinicians	Most patients should receive the recommended course of action	Different choices will be appropriate for different patients and clinicians must make greater effort in helping patients to arrive at a decision consistent with their values and preferences (shared decision-making)
Policy makers	The recommendation can be adopted as a policy in most situations	Policy making will require substantial debate and involvement of many stakeholders

RANZCOG [32]:

Table A-2: Certainty of recommendation RANZCOG

Certainty	
High certainty evidence comes from well-conducted studies, with minimal risk of bias and consistent results; further research is unlikely to change it.	⊕⊕⊕⊕ high
Moderate certainty suggests that there is sufficient evidence to support the estimate, but further research may still affect it; it comes from studies with some limitations, inconsistencies, or a possibility of bias.	⊕⊕⊕○ moderate
Low certainty indicates a limitation in the available evidence, which may be due to methodological flaws, indirectness or inconsistency of the evidence, or a high risk of bias. Further research may impact the confidence.	⊕⊕○○ low
Very low certainty implies that the available evidence is insufficient to undertake conclusions, and the true effect is likely to be unknown.	⊕○○○ very low

Strong recommendations are based on high or moderate certainty evidence. Conditional recommendations are based on low certainty evidence

Table A-3: Strength of recommendation RANZCOG

Type of recommendation	Description and features
Strong recommendation (GRADE option)	Interpretation: All or almost all informed people would choose the recommended option. Used when: high or moderate certainty that the effects clearly favour the recommended option, little variability in how effects are valued, other consequences favour the option. Wording: ‘should’, ‘should not’, ‘offer’, ‘do’, ‘do not’, ‘The GDG recommends’
Conditional recommendation (GRADE option)	Interpretation: Most informed people would choose the recommended option but a substantial number would not. Shared decision making is needed to ensure that those receiving care can make an informed values-based choice. May be conditional on values and preferences, resources, setting, or other conditions. Used when: either close balance between desirable and undesirable effects of the options, low or very low certainty, variable values (or uncertain) such that informed patients would make different choices, or other issues. Wording: ‘consider’, ‘The GDG suggests’.

NICE [33]

Table A-4: Strength of recommendation NICE

Type of recommendation	Description and features
Strong	is made when the committee concludes that the benefits clearly outweigh the harms for most people and the intervention is likely to be cost-effective, meaning the vast majority of practitioners and patients would choose this intervention based on the evidence.
Weak	is made when the balance between benefits and harms is closer and more uncertain, such that some people would choose the intervention while others would not, reflecting greater variability in individual circumstances and preferences.

In the GRADE approach, evidence is rated on a four-level scale (high, moderate, low, or very low) reflecting the degree of confidence that the available research accurately reflects the true effect of an intervention.

Table A-5: Certainty of recommendation RANZCOG

Certainty	Description and features
High	further research is very unlikely to change our recommendation
Moderate	further research may have an important impact on our confidence in the estimate of effect and may change the strength of our recommendation.
Low	further research is likely to have an important impact on our confidence in the estimate of effect and is likely to change the recommendation.
Very low	any estimate of effect is very uncertain and further research will probably change the recommendation.

AWMF[34]:

The recommendation expresses how strongly a certain medical action should be followed, based on weighing its benefits and risks, using wording like “shall”, “should” or “can” to indicate different levels of obligation.

A statement, by contrast, simply presents a professional observation or piece of information without giving a directive for action.

In a structured consensus process, authorised participants vote on the drafted statements and recommendations, during which wording may be revised.

The strength of the consensus is then determined based on the number of participants involved.

Table A-6: Strength of recommendation AWMF

Symbolism	Consensus strength	Percentage agreement
+++	Strong consensus	agreement among > 95% of participants
++	Consensus	agreement among > 75-95% of participants
+	Majority consensus	agreement among > 50-75% of participants
-	No consensus	agreement among ≤ 50% of participants

HSE [39]:

Table A-7: Strength and certainty of recommendation HSE

Grade of recommendation	Clarity of risk/benefit	Quality if supporting evidence	Implications
1A. Strong recommendation, high-quality evidence	Benefits clearly outweigh risk and burdens, or vice versa	Consistent evidence from well-performed randomised, controlled trials or overwhelming evidence of some other form. Further research is unlikely to change our confidence in the estimate of benefit and risk	Strong recommendations can apply to most patients in most circumstances without reservation. Clinicians should follow a strong recommendation unless a clear and compelling rationale for an alternative approach is present
1B. Strong recommendation, moderate-quality evidence	Benefits clearly outweigh risk and burdens, or vice versa	Evidence from randomised, controlled trials with important limitations (inconsistent results, methodologic flaws, indirect or imprecise), or very strong evidence from some other research design. Further research (if performed) is likely to have an impact on our confidence in the estimate of benefit and risk and may change the estimate	Strong recommendation and applies to most patients. Clinicians should follow a strong recommendation unless a clear and compelling rationale for an alternative approach is present
1C. Strong recommendation, low-quality evidence	Benefits appear to outweigh risk and burdens, or vice versa	Evidence from observational studies, unsystematic clinical experience, or from randomised, controlled trials with serious flaws. Any estimate of effect is uncertain	Strong recommendation that applies to most patients. Some of the evidence base supporting the recommendation is, however, of low quality
2A. Weak recommendation, high-quality evidence	Benefits closely balanced with risks and burdens	Consistent evidence from well-performed randomised, controlled trials or overwhelming evidence of some other form. Further research is unlikely to change our confidence in the estimate of benefit and risk	Weak recommendation: best action may differ depending on circumstances or patients or societal values
2B. Weak recommendation, moderate-quality evidence	Benefits closely balanced with risks and burdens, some uncertainty in the estimates of benefits, risks and burdens	Evidence from randomised, controlled trials with important limitations (inconsistent results, methodologic flaws, indirect or imprecise), or very strong evidence from some other research design. Further research (if performed) is likely to have an impact on our confidence in the estimate of benefit and risk and may change the estimate	Weak recommendation; alternative approaches likely to be better for some patients under some circumstances
2C. Weak recommendation, low-quality evidence	Uncertainty in the estimates of benefits, risks, and burdens; benefits may be closely balanced with risks and burdens	Evidence from observational studies, unsystematic clinical experience, or from randomised, controlled trials with serious flaws. Any estimate of effect is uncertain	Very weak recommendation: other alternatives may be equally reasonable
Best practice	A recommendation that is sufficiently obvious that the desirable effects outweigh undesirable effects, despite the absence of direct evidence, such that the grading of evidence is unnecessary		

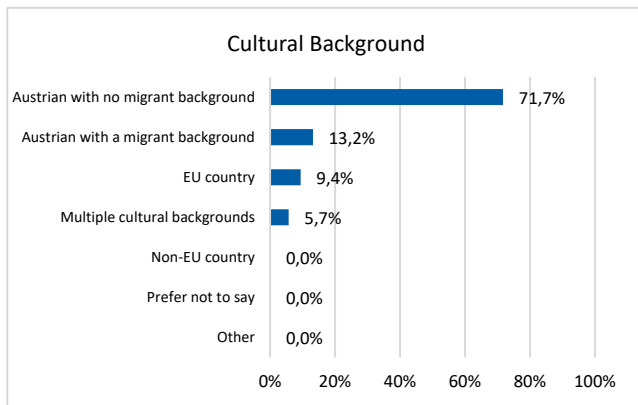


Figure A-1: Cultural Background

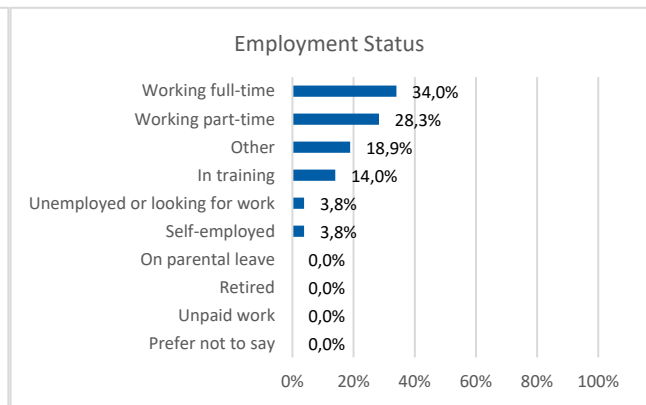


Figure A-2: Employment Status

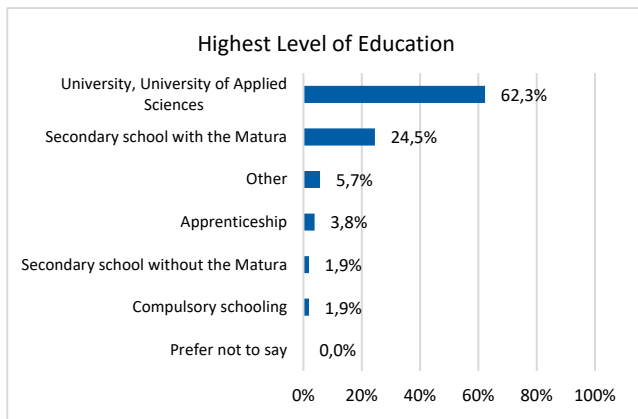


Figure A-3: Highest Level of Education

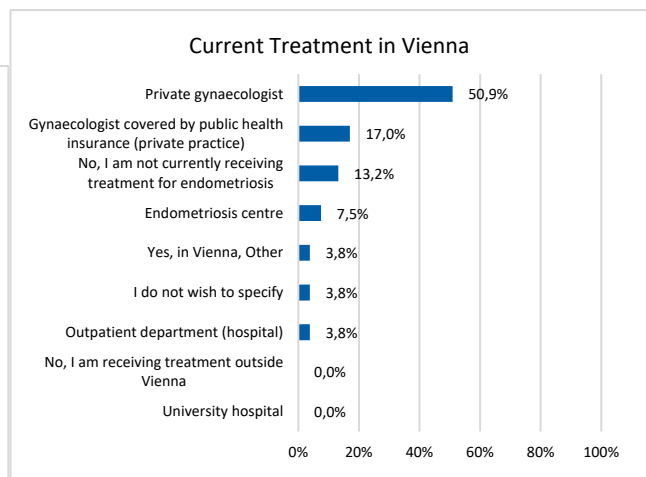


Figure A-4: Current Treatment in Vienna

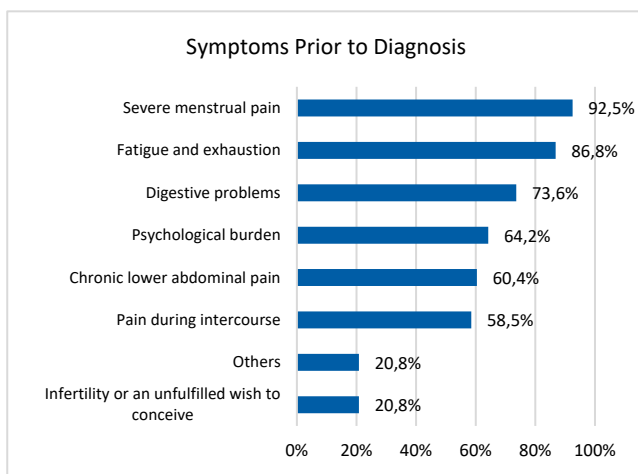


Figure A-5: Symptoms Prior to Diagnosis

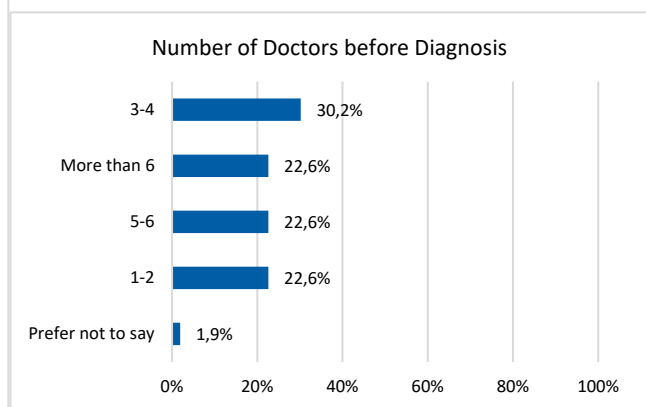


Figure A-6: Number of Doctors before Diagnosis

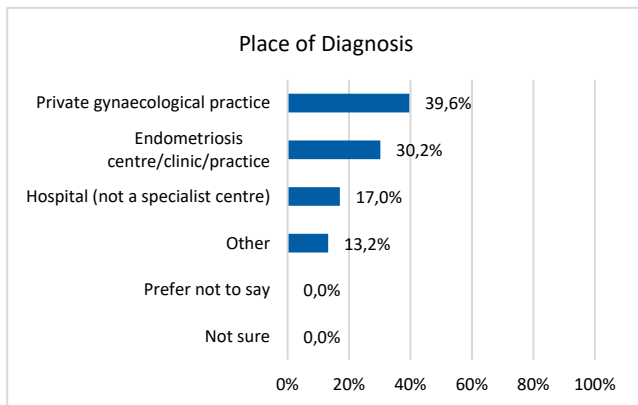


Figure A-7: Place of Diagnosis

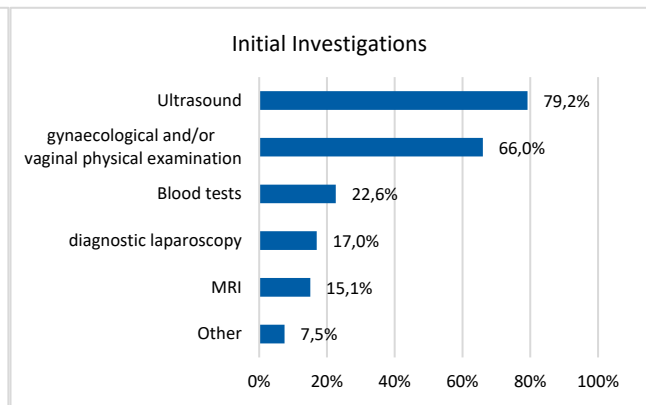


Figure A-8: Initial Investigations

A-II Patient Survey Graphs

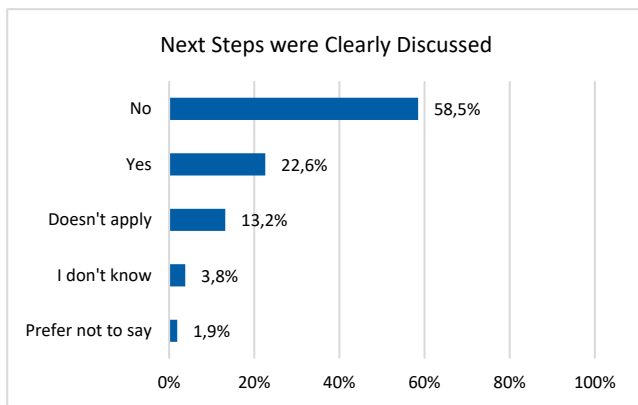


Figure A-9: Next Steps were Discussed

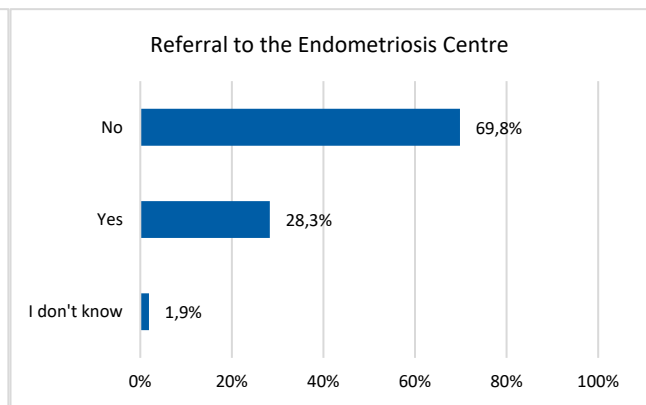


Figure A-10: Referral to Endometriosis Centre

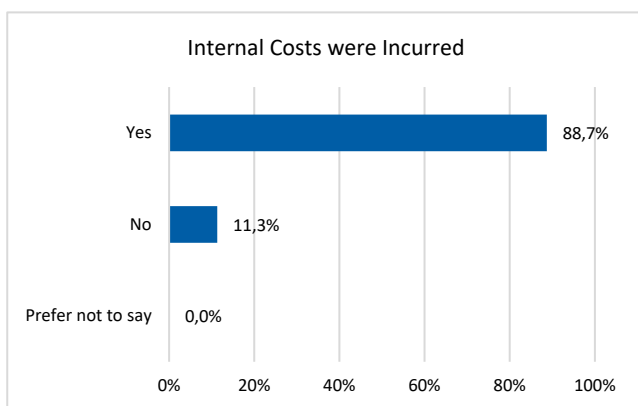


Figure A-11: Internal Costs were Incurred

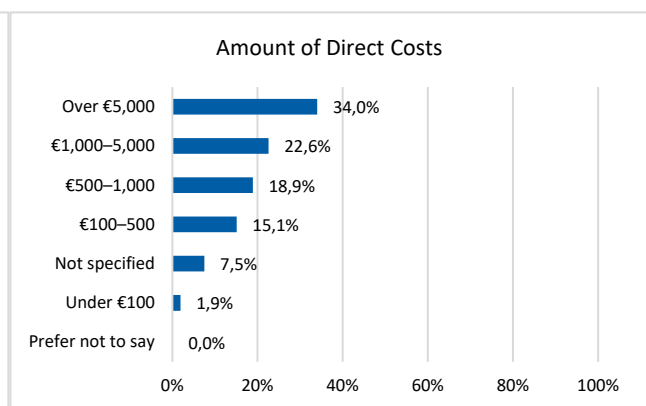


Figure A-12: Amount of Direct Costs

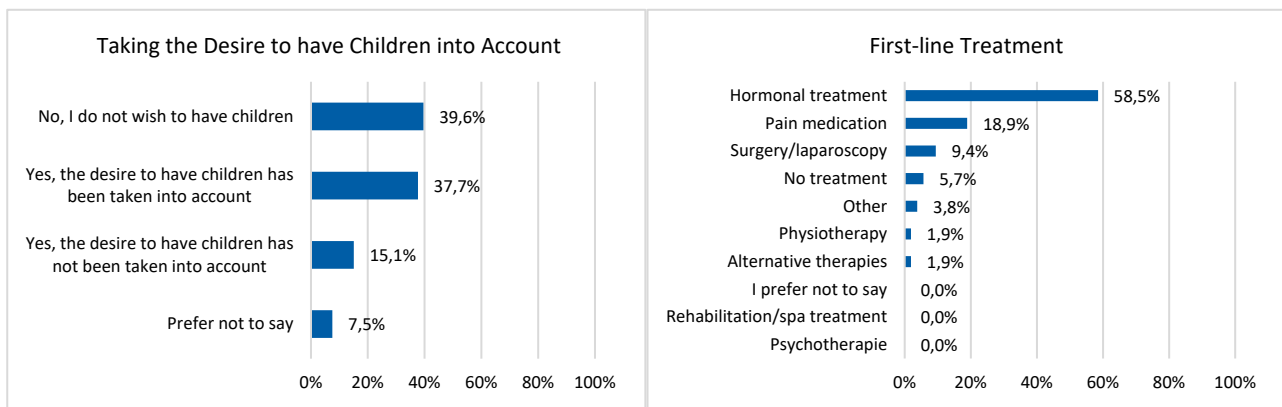


Figure A-13: Taking the Desire to have Children into Account Figure A-14: First-line Treatment

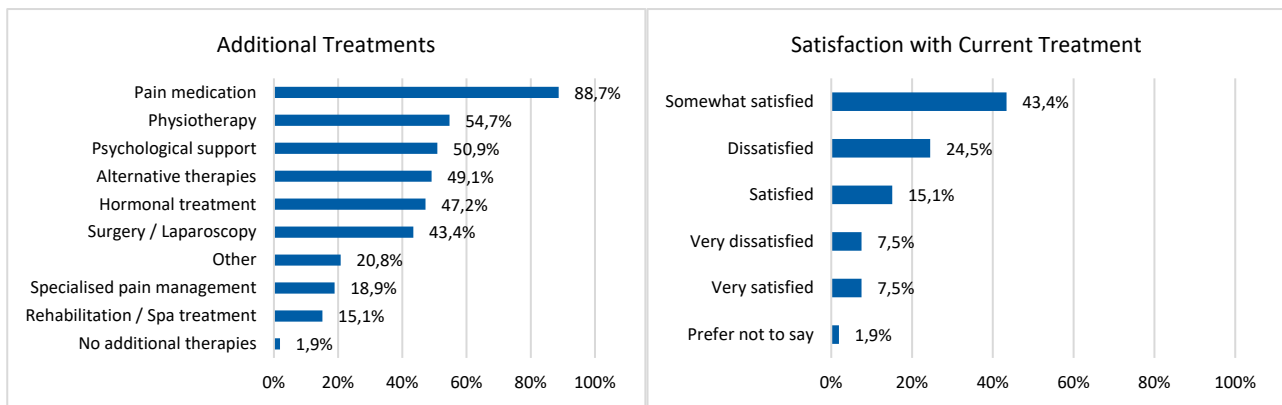


Figure A-15: Additional Treatment

Figure A-16; Satisfaction with Current Treatment

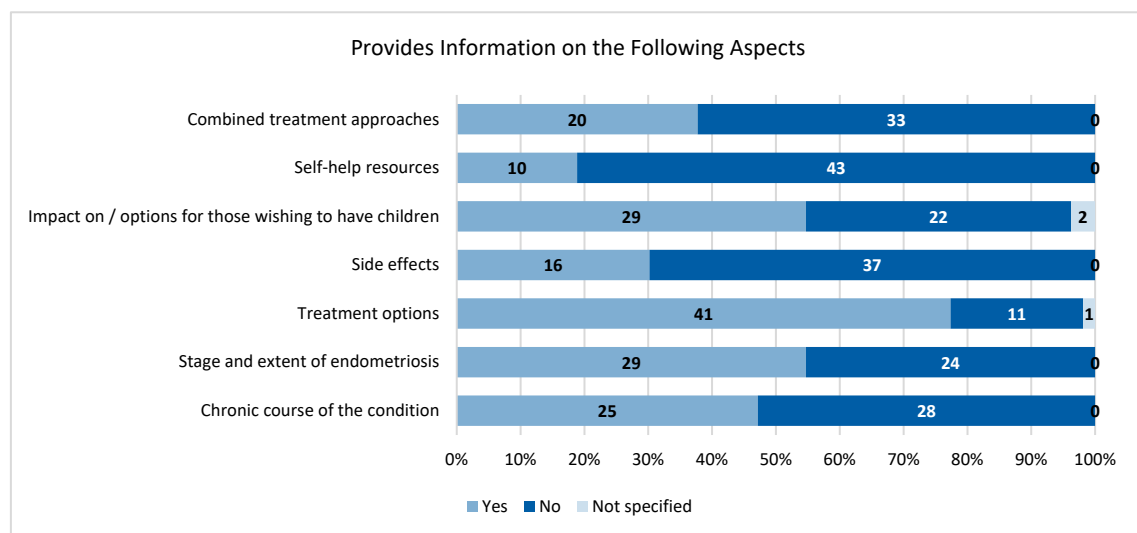


Figure A-17: Provides Information in the Following Aspects

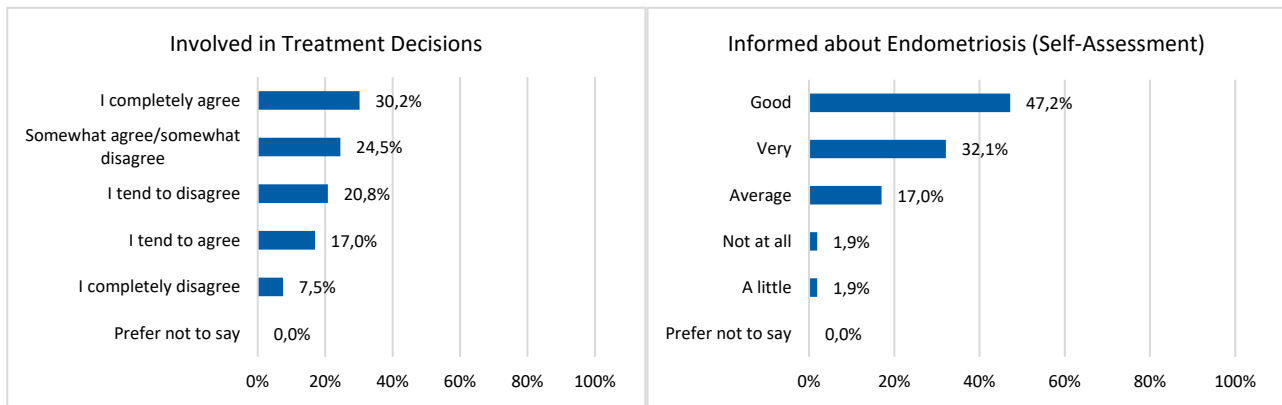


Figure A-18: Involved in Treatment Decisions

Figure A-19: Informed about Endometriosis

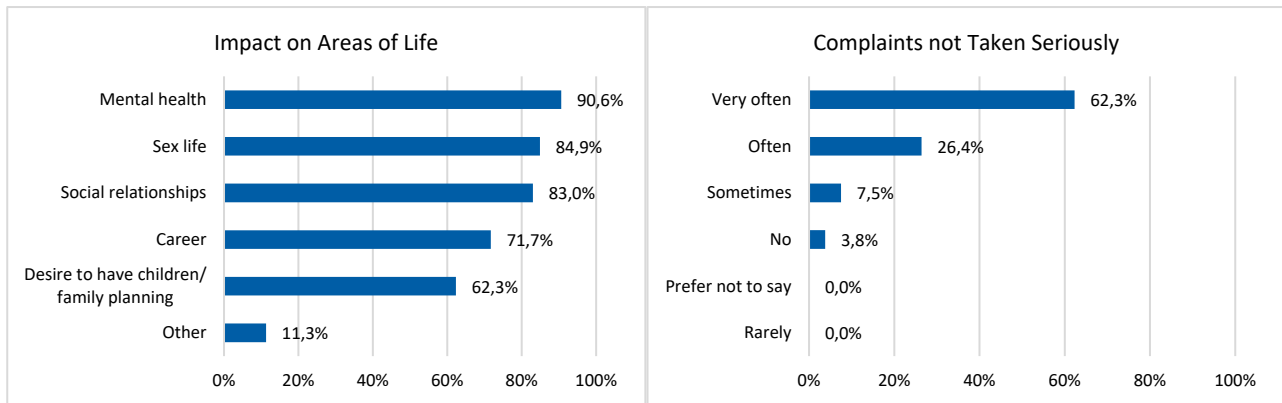


Figure A-20: Impact on Areas of Life

Figure A-21: Complaints not Taken Seriously

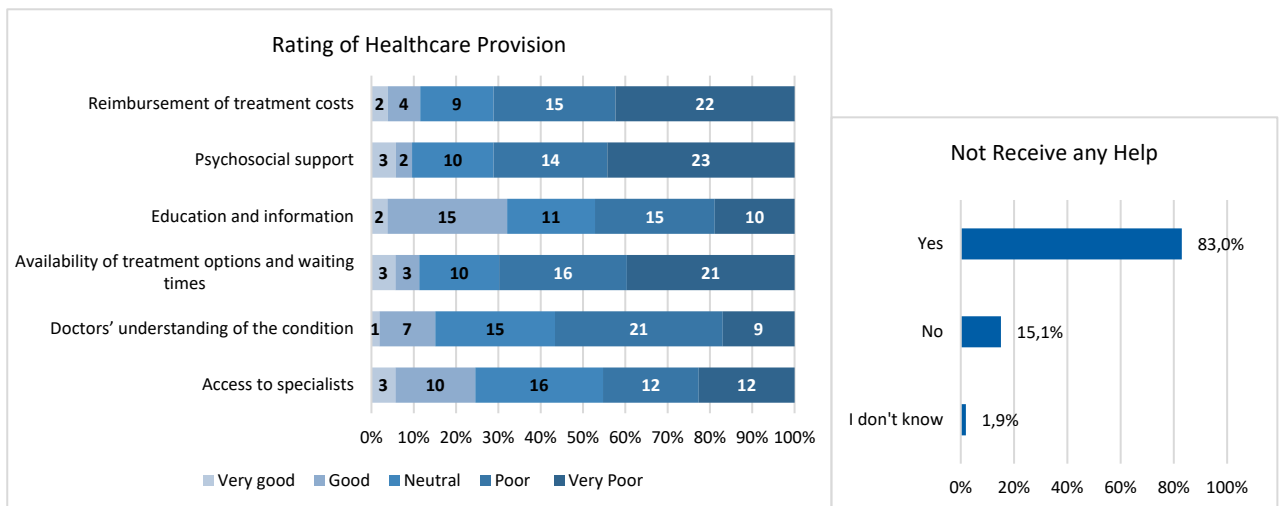


Figure A-22: Rating of Healthcare Provision

Figure A-23: Not Receive any Help

A-III Healthcare Provider Survey Graphs

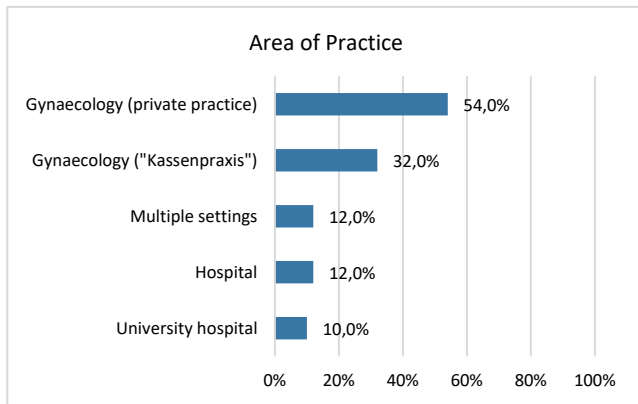


Figure A-24: Area of Practice

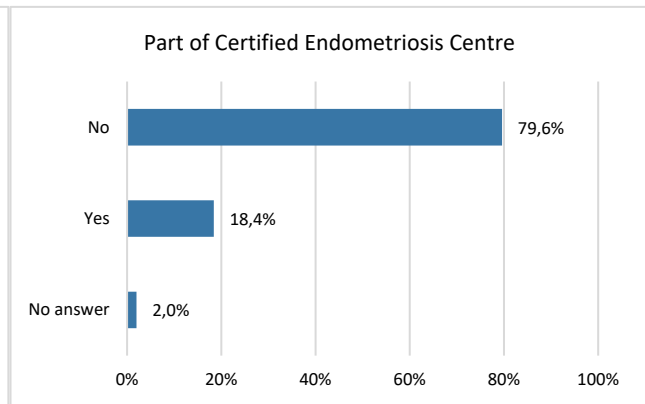


Figure A-25: Part of Endometriosis Centre

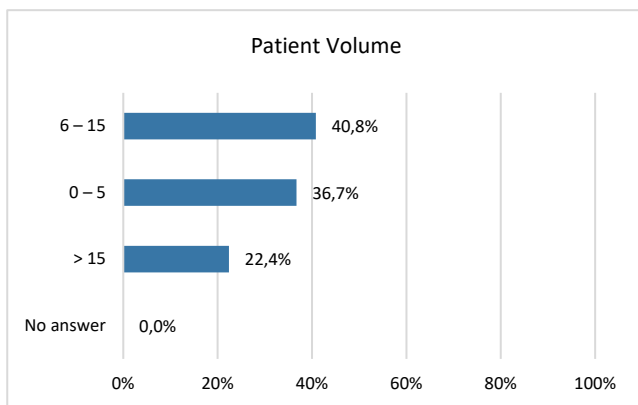


Figure A-26: Patient Volume

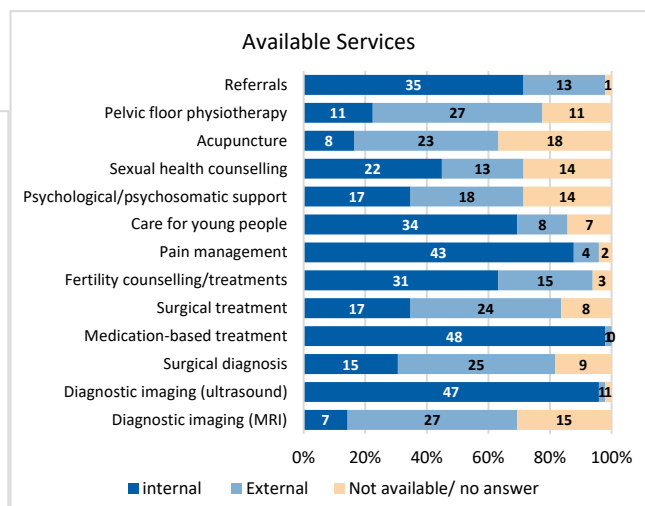


Figure A-27: Available Service

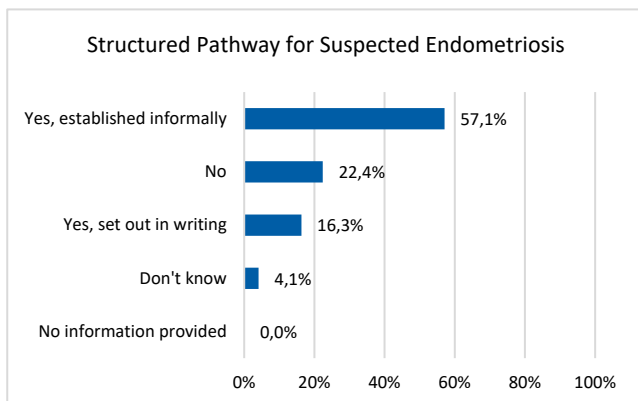


Figure A-28: Structured Pathway for Endometriosis

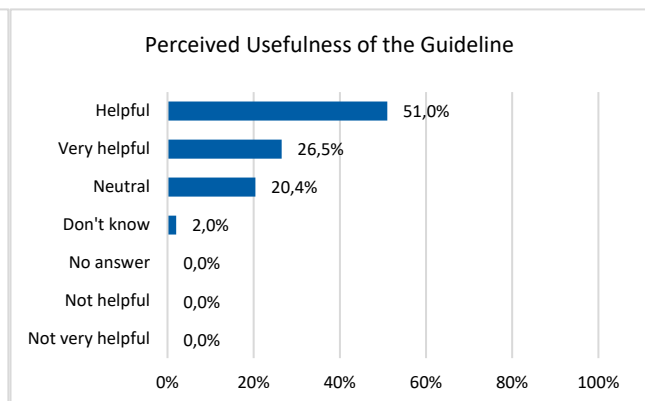


Figure A-29: Perceived Usefulness of Guidelines

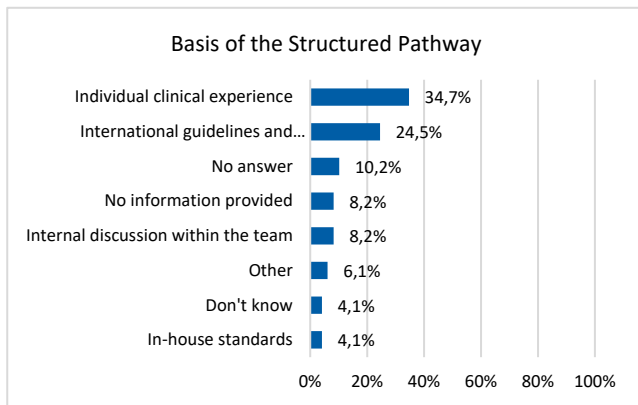


Figure A-30: Basis of Structured Pathway

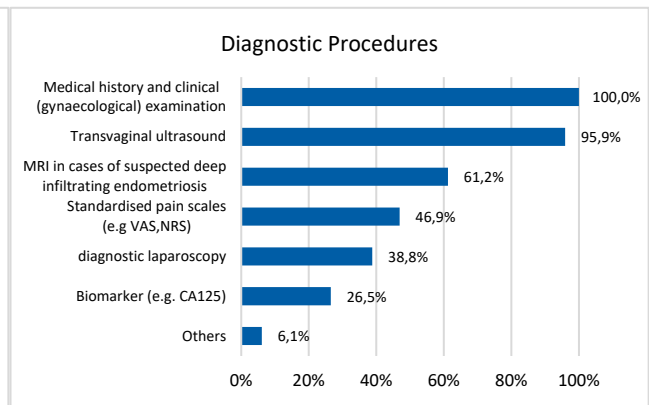


Figure A-31: Diagnostic Procedure

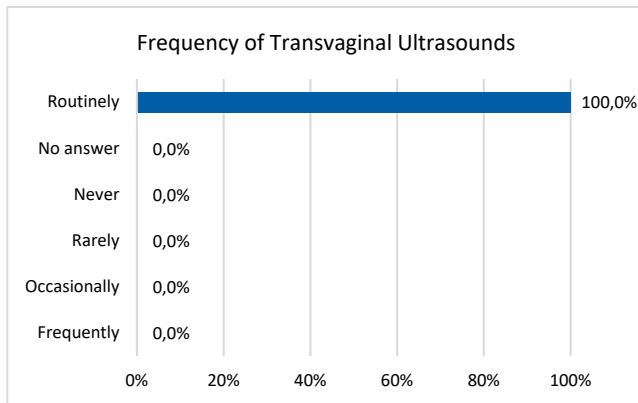


Figure A-32: Frequency of Transvaginal Ultrasounds

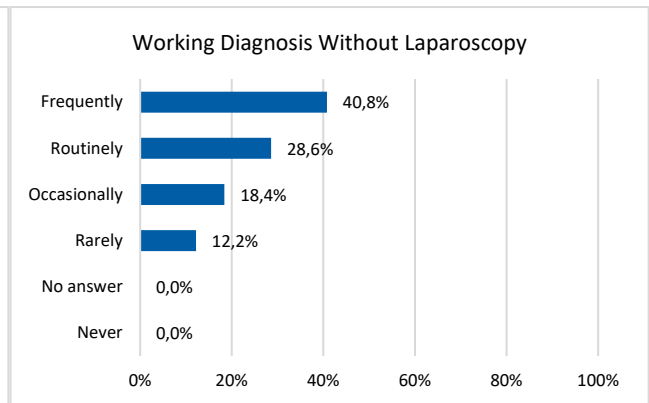


Figure A-33: Working Diagnosis without Laparoscopy

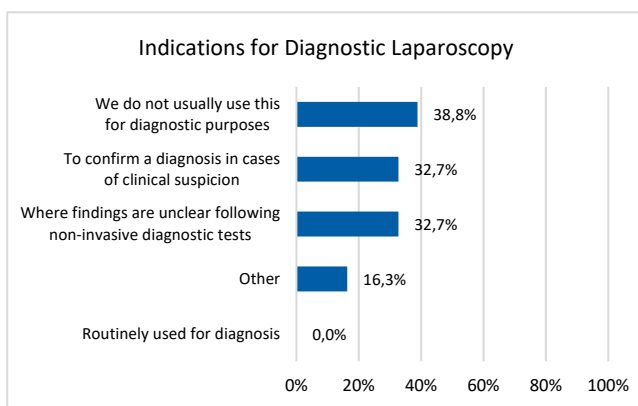


Figure A-34: Indication for Diagnostic Laparoscopy

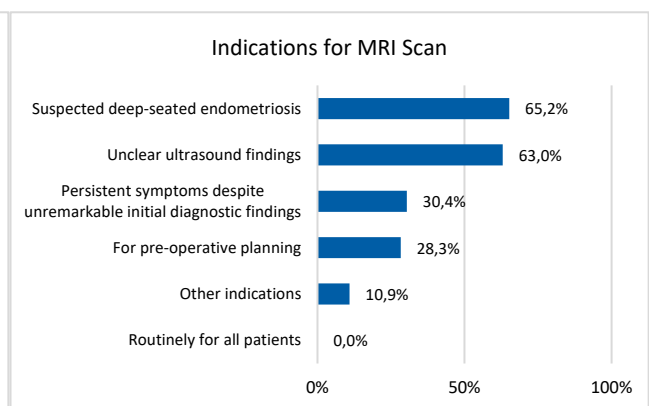


Figure A-35: Indication for MRI Scan

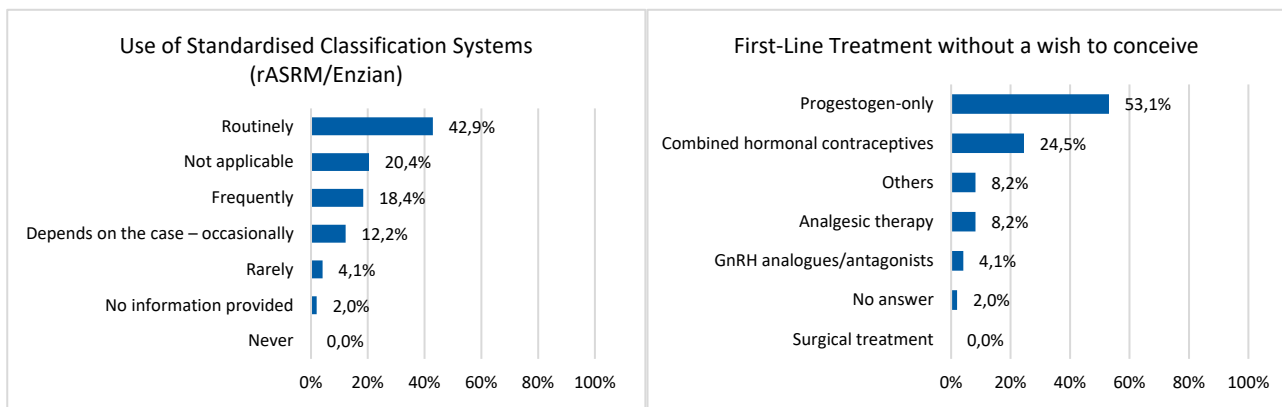


Figure A-36: Use of Standardised Classification System

Figure A-37: First-line Treatment without a wish to conceive

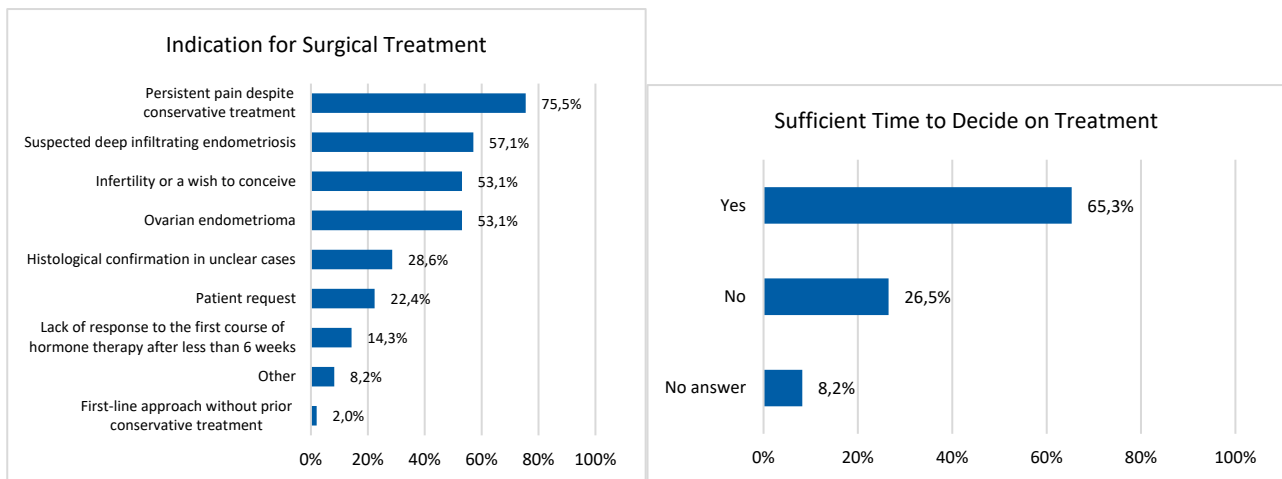


Figure A-38: Indication for Surgical Treatment

Figure A-39: Sufficient Time for Treatment Decision

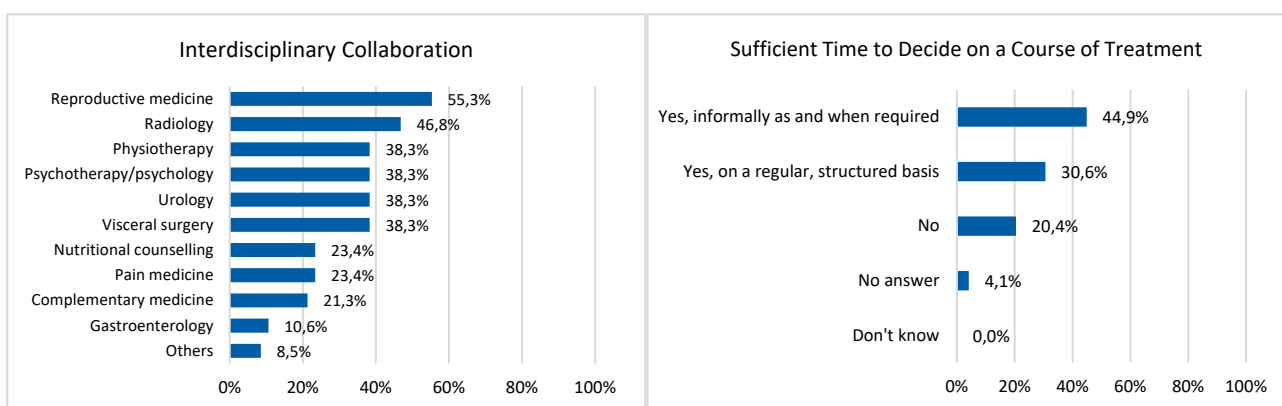


Figure A-40: Interdisciplinary Collaboration

Figure A-41: Sufficient Time to Decide on a Course of Treatment

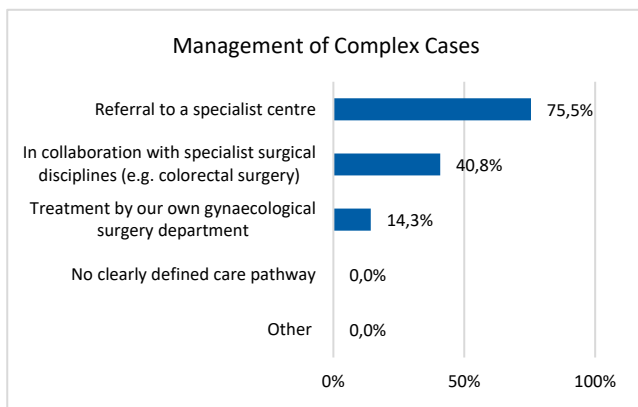


Figure A-42: Management of Complex Cases

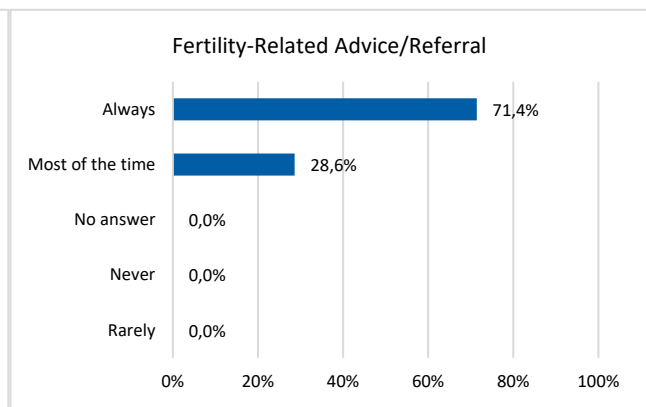


Figure A-43: Fertility-related Referral

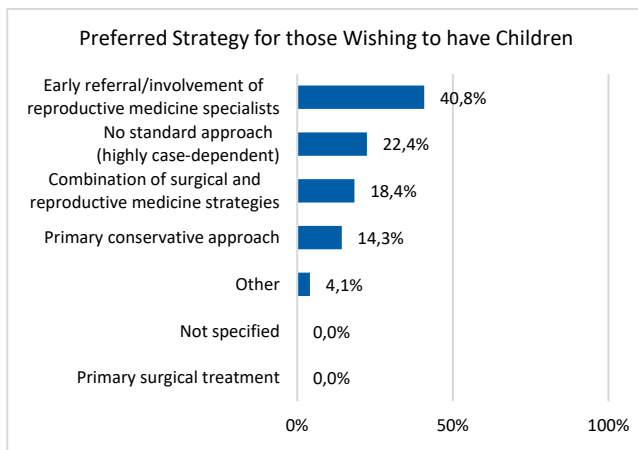


Figure A-44: Preferred Strategy for those Wishing to have Children

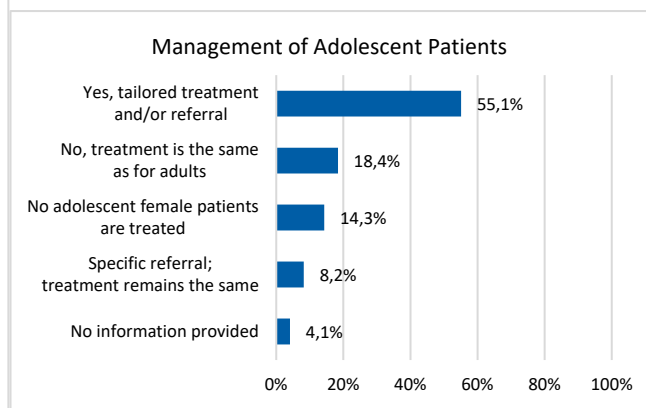


Figure A-45: Management of Adolescent Patients

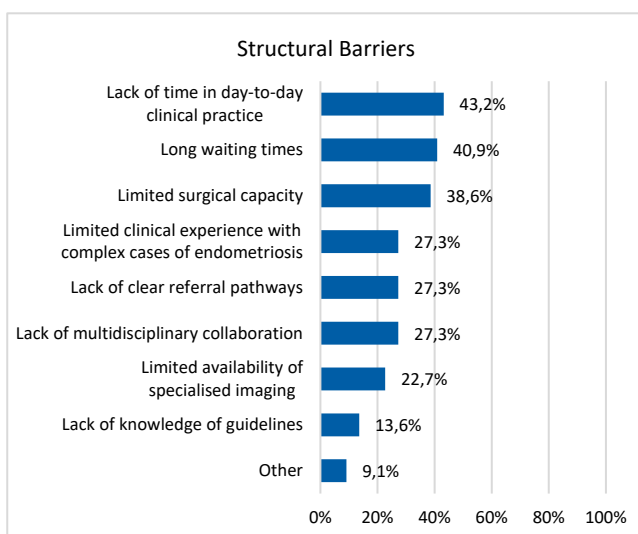


Figure A-46: Structural Barriers

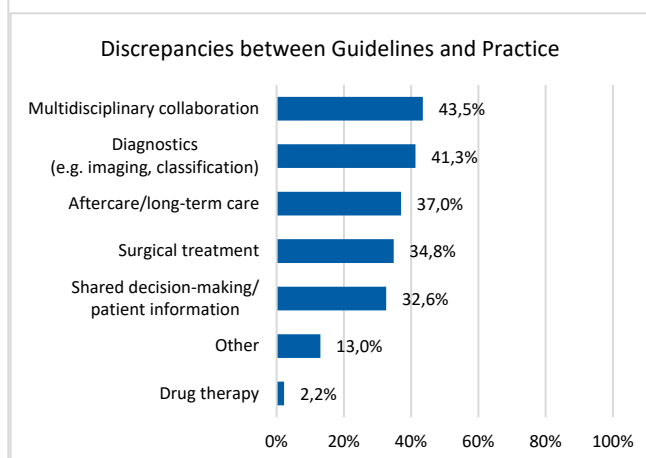


Figure A-47: Discrepancies between Guidelines and Practice

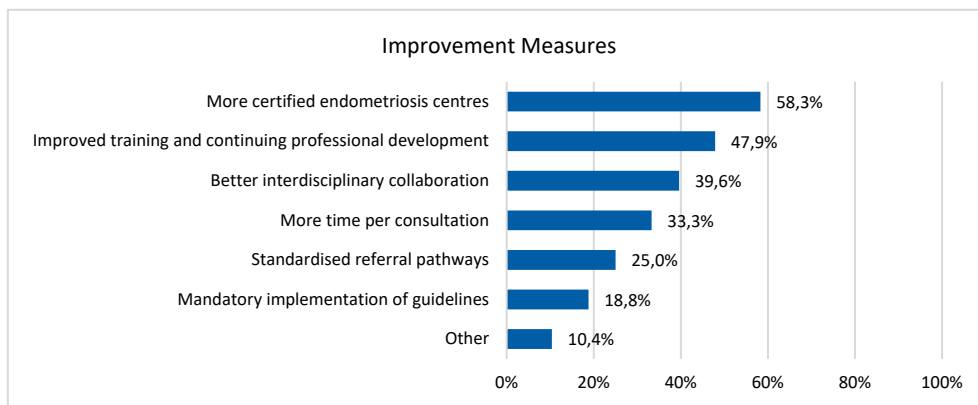


Figure A-48: Improvement Measures

A-IV Surveys

Patient Survey (German Version)

Persönliche Angaben

1. Wie alt sind Sie? _____ Jahre
2. Welchen kulturellen Hintergrund haben Sie?
 - ☐ Österreichisch ohne Migrationshintergrund
 - ☐ Österreichisch mit Migrationshintergrund
 - ☐ EU-Land
 - ☐ Nicht-EU-Land
 - ☐ Mehrere kulturelle Hintergründe
 - ☐ Andere: _____
 - ☐ Möchte ich nicht angeben
3. Sind Sie derzeit hauptsächlich ...?
 - ☐ Vollzeit berufstätig (mind. 35 Stunden/Woche und mehr)
 - ☐ Teilzeit berufstätig (weniger als 35 Stunden/Woche)
 - ☐ Selbständig
 - ☐ in Ausbildung (Schule, Lehre, Studium oder Ähnliches)
 - ☐ in Elternkarenz
 - ☐ arbeitslos bzw. auf Arbeitssuche
 - ☐ unbezahlte Arbeit (Haushalt, Kinderbetreuung und/oder Pflege von Angehörigen)
 - ☐ in Pension
 - ☐ Anderes: _____
 - ☐ möchte ich nicht angeben
4. Was ist Ihr höchster Bildungsabschluss?
 - ☐ Pflichtschule
 - ☐ Lehre
 - ☐ weiterführende Schule ohne Matura
 - ☐ weiterführende Schule mit Matura

- ☐ Universität, Fachhochschule
- ☐ Sonstige: _____
- ☐ möchte ich nicht angeben

Diagnose und Behandlung

5. Werden Sie derzeit wegen Ihrer Endometriose in Wien behandelt?
 - ☐ Nein, ich bin aktuell nicht in Behandlung für Endometriose
 - ☐ Ja, in Wien: _____
 - ☐ Kassen-Gynäkolog:in (niedergelassene Praxis)
 - ☐ Privat-Gynäkolog:in
 - ☐ Ambulanz (Krankenhaus)
 - ☐ Endometriose-Zentrum, und zwar: _____
 - ☐ Universitätsklinik
 - ☐ Sonstiges: _____
 - ☐ Nein, ich bin außerhalb von Wien in Behandlung
 - ☐ Möchte ich nicht angeben
6. Wie lange hat es gedauert, von Ihren ersten Symptomen, bis Sie eine Endometriose Diagnose erhielten? ____ Jahre
7. Welche Beschwerden hatten sie vor der Diagnose?
 - ☐ Schmerzen beim Geschlechtsverkehr
 - ☐ Starke Regelschmerzen
 - ☐ Unfruchtbarkeit/unerfüllter Kinderwunsch
 - ☐ Chronische Unterbauchschmerzen
 - ☐ Verdauungsprobleme
 - ☐ Müdigkeit/Erschöpfung
 - ☐ Psychische Belastung
 - ☐ Andere: _____
 - ☐ Möchte ich nicht angeben
8. Bei wie vielen Ärzt:innen oder medizinischen Einrichtungen waren Sie, bevor Ihre Endometriose diagnostiziert wurde?
 - ☐ 1-2
 - ☐ 3-4
 - ☐ 5-6
 - ☐ Mehr als 6
 - ☐ Möchte ich nicht angeben
9. Wo wurde die Diagnose „Endometriose“ gestellt?
 - ☐ Niedergelassene gynäkologische Praxis
 - ☐ Endometriose-Zentrum/Klinik/Praxis
 - ☐ Krankenhaus (kein spezialisiertes Zentrum)
 - ☐ Sonstiges: _____
 - ☐ Bin mir nicht sicher
 - ☐ Möchte ich nicht angeben
10. Welche Untersuchungen wurden als erstes bei Ihnen gemacht? (Mehrfachauswahl möglich)
 - ☐ Ultraschall
 - ☐ MRT

- ☐ Laparoskopie (Spiegelung der Bauchhöhle)
 - ☐ Körperliche Untersuchung (gynäkologischer/vaginale Untersuchung)
 - ☐ Bluttests
 - ☐ Andere: _____
 - ☐ Möchte ich nicht angeben
11. Wenn Ihre ersten Untersuchungen unauffällig waren, die Beschwerden aber anhielten:
Hat Ihr Arzt/Ihre Ärztin das weitere Vorgehen klar mit Ihnen besprochen?
- ☐ Ja
 - ☐ Nein
 - ☐ Weiß ich nicht
 - ☐ Trifft nicht zu
 - ☐ Möchte ich nicht angeben
12. Wenn Endometriose diagnostiziert bzw. vermutet wurde, wurden Sie an ein spezialisiertes Endometriose-Zentrum überwiesen?
- ☐ Ja
 - ☐ Nein
 - ☐ Weiß ich nicht
13. Gab es Zeiten, in denen Sie mit Beschwerden keine Hilfe bekommen haben?
- ☐ Ja, weil:
 - ☐ Nein
 - ☐ Möchte ich nicht angeben
 - ☐
14. Sind Ihnen im Zusammenhang mit Ihrer Endometriose-Diagnose oder Behandlung persönliche Kosten entstanden, die nicht von der Krankenversicherung übernommen wurden?
Falls ja: In welchen Bereichen sind Kosten entstanden?
- ☐ Ja, und zwar für: _____
 - ☐ Nein
 - ☐ Möchte ich nicht angeben
- 14a Falls ja, Wie hoch schätzen Sie Ihre Eigenkosten insgesamt (Behandlungen, Medikamente, Laboruntersuchungen, etc.)?
- ☐ Unter 100 €
 - ☐ 100-500 €
 - ☐ 500-1.000 €
 - ☐ 1.000-5.000 €
 - ☐ Über 5.000 €
 - ☐ Möchte ich nicht angeben
15. Hatten oder haben Sie einen Kinderwunsch, und wurde dieser bei Ihrer Behandlung berücksichtigt?
- ☐ Ja, ich hatte/habe einen Kinderwunsch, und dieser wurde berücksichtigt
 - ☐ Ja, ich hatte/habe einen Kinderwunsch, aber dieser wurde nicht berücksichtigt
 - ☐ Nein, ich hatte/habe keinen Kinderwunsch
 - ☐ Keine Angabe
16. Welche Behandlung haben Sie als erstes erhalten? (bitte nur eine Option auswählen)
- ☐ Schmerzmedikamente
 - ☐ Hormonelle Behandlung (Pille/Gestagene/GnRH-Analoga)
 - ☐ Operation/Bauchspiegelung

- ☐ Alternative Therapien (z. B. Akupunktur)
- ☐ Psychotherapie
- ☐ Physiotherapie
- ☐ Reha/Kur
- ☐ Andere: _____
- ☐ Keine Behandlung
- ☐ Möchte ich nicht angeben

17. Welche Behandlungen haben Sie zusätzlich bereits ausprobiert? (Mehrfachauswahl möglich)

- ☐ Schmerzmedikamente
- ☐ Hormonelle Behandlung (Pille/Gestagene/GnRH-Analoga)
- ☐ Operation/ Bauchspiegelung
- ☐ Alternative Therapien (z.B. Akupunktur)
- ☐ Physiotherapie
- ☐ Reha/Kur
- ☐ Spezielle Schmerztherapie
- ☐ Psychologische Unterstützung
- ☐ Anderes: _____
- ☐ Keine Therapie
- ☐ Möchte ich nicht angeben

18. Wie zufrieden sind Sie mit Ihrer aktuellen Behandlung?

- ☐ Sehr zufrieden
- ☐ Zufrieden
- ☐ Teilweise zufrieden
- ☐ Unzufrieden
- ☐ Sehr unzufrieden
- ☐ Möchte ich nicht angeben

Informationsstand und Aufklärung

19. Wurden Sie über folgende Aspekte informiert?

	Ja	Nein	Möchte ich nicht angeben
Chronischer Verlauf der Erkrankung	☐	☐	☐
Stadium und Ausmaß der Endometriose	☐	☐	☐
Behandlungsmöglichkeiten	☐	☐	☐
Nebenwirkungen	☐	☐	☐
Einfluss auf und Optionen bei Kinderwunsch	☐	☐	☐
Selbsthilfeangebote	☐	☐	☐
Kombinierte Behandlungsansätze (z. B. Physiotherapie, etc)	☐	☐	☐

20. Ich hatte das Gefühl, in die Entscheidung über meine Behandlung eingebunden zu sein.

- ☐ Stimme voll zu
- ☐ Stimme eher zu
- ☐ Teils/teils
- ☐ Stimme eher nicht zu
- ☐ Stimme überhaupt nicht zu
- ☐ Möchte ich nicht angeben

21. Wie gut fühlen Sie sich über Endometriose informiert?

- ☐ Sehr
- ☐ Gut
- ☐ Mittelmäßig
- ☐ Wenig
- ☐ Gar nicht
- ☐ Möchte ich nicht angeben

22. Was hätte bei der Information über die Krankheit und Ihrer Einbindung in Entscheidungen zur Therapie besser laufen können? Beschreiben Sie bitte kurz, wie der Informations- und Involvierungsprozess Ihrer Meinung nach besser ablaufen kann, oder machen Sie ein X, wenn Sie diese Frage überspringen wollen:

Psychosoziale Auswirkungen:

23. Hat die Endometriose Auswirkungen auf folgende Lebensbereiche? (Mehrfachauswahl möglich)

- ☐ Berufliche Karriere
- ☐ Soziale Beziehungen
- ☐ Kinderwunsch/Familienplanung
- ☐ Sexualleben
- ☐ Psychische Gesundheit
- ☐ Andere: _____
- ☐ Möchte ich nicht angeben

24. Hatten Sie jemals das Gefühl, dass Ihre Beschwerden von medizinischem Fachpersonal nicht ausreichend ernst genommen wurden?

- ☐ Nein
- ☐ Sehr oft
- ☐ Oft
- ☐ Manchmal
- ☐ Selten
- ☐ Möchte ich nicht angeben

Erfahrungen und Verbesserungspotenziale

25. Was waren Ihre größten Herausforderungen im Umgang mit Endometriose?
(Bitte beschreiben Sie ausführlich):

26. Was läuft bereits gut in der Versorgung? Bitte beschreiben Sie Aspekte, die Sie positiv erleben:

27. Bewerten Sie folgende Aspekte der Versorgung (1 = sehr gut, 5 = sehr schlecht):

Aspekt	Bewertung (1-5)
Zugänglichkeit von Spezialist:innen	☐
Verständnis der Erkrankung bei Ärzt:innen	☐
Verfügbarkeit von Behandlungsoptionen und Wartezeiten	☐
Aufklärung und Information	☐
Psychosoziale Unterstützung	☐
Kostenerstattung für Behandlungen	☐

Gibt es noch etwas, das Sie uns gerne mitteilen würden, das noch nicht gefragt wurde?:

Healthcare Provider Survey (German Version)

1. Allgemeine Angaben zur Einrichtung & Praxis
 - ☐ In welchem Bereich sind Sie überwiegend tätig?
 - ☐ Gynäkologie (Privatpraxis)
 - ☐ Gynäkologie (Kassenpraxis)
 - ☐ Krankenhaus
 - ☐ Universitätsklinik
 - ☐ Tätigkeit in mehreren Settings, bitte angeben:
 - ☐ Keine Angabe
2. Sind Sie Teil eines zertifizierten Endometriose Zentrums?
 - ☐ Ja
 - ☐ Nein
 - ☐ Keine Angabe
3. Wie viele Patient:innen mit Verdacht auf oder diagnostizierter Endometriose sehen Sie durchschnittlich pro Monat?
 - ☐ 0-5
 - ☐ 6-15
 - ☐ > 15
 - ☐ Keine Angabe
4. Welche der folgenden Leistungen sind in Ihrer Einrichtung verfügbar – entweder als eigenes Angebot oder im Rahmen einer multidisziplinären Zusammenarbeit? (Mehrfachauswahl)

Leistung	Intern	Extern	Nicht verfügbar
Bildgebende Diagnostik	☐	☐	☐
Operative Diagnostik	☐	☐	☐
Medikamentöse Therapie	☐	☐	☐
Operative Therapie	☐	☐	☐
Kinderwunschberatung/Behandlungen	☐	☐	☐
Schmerzmedizin	☐	☐	☐
Versorgung von Jugendlichen	☐	☐	☐
Psychologische/psychosomatische Betreuung	☐	☐	☐
Sexualmedizinische Beratung	☐	☐	☐
Akupunktur	☐	☐	☐
Beckenbodenphysiotherapie	☐	☐	☐
Überweisung	☐	☐	☐

Diagnostische Praxis

5. Gibt es in Ihrer Einrichtung einen strukturierten Ablauf bei Verdacht auf Endometriose?
 - ☐ Ja, schriftlich festgelegt
 - ☐ Ja, informell etabliert
 - ☐ Nein
 - ☐ Weiß nicht
 - ☐ Keine Angabe
- 5a. Wenn ja, worauf basiert dieser Ablauf?

- ☐ Interne hauseigene Standards
 - ☐ Internationale Leitlinien-Empfehlungen, bitte angeben welche:
 - ☐ Individuelle klinische Erfahrung
 - ☐ Interner Austausch im Team
 - ☐ Sonstiges: _____
 - ☐ Weiß nicht
 - ☐ Keine Angabe
6. Empfinden Sie die Endometriose-Leitlinie als hilfreich bei der Diagnostik und Behandlung von Endometriosepatient:innen?
- ☐ Sehr hilfreich
 - ☐ Hilfreich
 - ☐ Neutral
 - ☐ Wenig hilfreich
 - ☐ Nicht hilfreich
 - ☐ Kenne ich nicht
 - ☐ Keine Angabe
7. Welche Symptome bzw. Symptombereiche klären Sie bei Verdacht auf Endometriose ab?
8. Welche diagnostischen Verfahren setzen Sie bei Verdacht auf Endometriose typischerweise ein? (Mehrfachauswahl möglich, bitte berücksichtigen Sie sowohl Leistungen im eigenen Setting als auch solche, die über Weiterüberweisung erfolgen)
- ☐ Anamnese und klinische (gynäkologische) Untersuchung
 - ☐ Transvaginaler Ultraschall
 - ☐ MRT bei Verdacht auf tiefe infiltrierende Endometriose
 - ☐ Diagnostische Laparoskopie
 - ☐ Biomarker (z.B. CA125)
 - ☐ Standardisierte Schmerzskalen (z.B. VAS, NRS)
 - ☐ Sonstige: _____
 - ☐ Keine Angabe
9. Wie häufig setzen Sie bei Verdacht auf Endometriose zur Erstdiagnostik einen transvaginalen Ultraschall ein? (Bitte berücksichtigen Sie sowohl Untersuchungen im eigenen Setting als auch über Weiterüberweisung)
- ☐ Routinemäßig
 - ☐ Häufig
 - ☐ Gelegentlich
 - ☐ Selten
 - ☐ Nie
 - ☐ Keine Angabe
10. Wie häufig wird in ihrem Setting die Arbeitsdiagnose Endometriose ohne vorherige diagnostische Laparoskopie gestellt?
- ☐ Routinemäßig
 - ☐ Häufig
 - ☐ Gelegentlich
 - ☐ Selten
 - ☐ Nie
 - ☐ Keine Angabe

11. Unter welchen Umständen wird in Ihrem Setting typischerweise eine diagnostische Laparoskopie bei Verdacht auf Endometriose erwogen? (Mehrfachauswahl)
- ☐ Routinemäßig zur Diagnosestellung
 - ☐ Bei Unklarem Befund nach nicht-invasiver Diagnostik
 - ☐ Zur diagnostischen Sicherung bei klinischem Verdacht
 - ☐ Wird von uns in der Regel nicht zur Diagnostik eingesetzt
 - ☐ Andere: _____
 - ☐ keine Angabe
12. Unter welchen Umständen veranlassen sie typischerweise eine MRT-Untersuchung? (Mehrfachauswahl)
- ☐ Verdacht auf tiefe infiltrierende Endometriose
 - ☐ Unklarer Ultraschall Befund
 - ☐ Andauernde Symptomatik trotz unauffälliger Erstdiagnostik
 - ☐ Zur präoperativen Planung
 - ☐ Routinemäßig bei allen Patient:innen
 - ☐ Andere Indikationen: _____
 - ☐ Keine Angabe
13. Wenn Operation: Wie häufig wird bei operativ behandelten Endometriosefällen eine standardisierte Klassifikation dokumentiert (z. B. rASRM oder #Enzian)
- ☐ Routinemäßig
 - ☐ Häufig
 - ☐ Fallabhängig-gelegentlich
 - ☐ Selten
 - ☐ Nie
 - ☐ Nicht zutreffend (keine operative Tätigkeit)
 - ☐ Keine Angabe
14. Welche Kompetenzen wären aus Ihrer Sicht für eine qualitativ hochwertige Diagnostik besonders wichtig?

Therapie

15. Welche Therapieoption setzen Sie bei/nach Erstdiagnose symptomatischer Endometriose ohne akuten Kinderwunsch am häufigsten ein?
- ☐ Kombinierte hormonelle Kontrazeptiva
 - ☐ Reine Gestagenpräparate
 - ☐ GnRH-Analoga/-Antagonisten
 - ☐ Analgetische Therapie
 - ☐ Operative Therapie
 - ☐ Andere: _____
 - ☐ Keine Angabe
16. Unter welchen Umständen wird in Ihrem Setting typischerweise eine operative Therapie der Endometriose erwogen? (Mehrfachauswahl)
- ☐ Anhaltende Schmerzen trotz konservativer Therapie
 - ☐ Erstdiagnose einer Endometriose ohne vorherige konservative Therapie
 - ☐ Verdacht auf tiefe infiltrierende Endometriose bzw. Organbeteiligung
 - ☐ Ovarielle Raumforderung /Endometriom
 - ☐ Ausbleibendes Ansprechen auf die erste hormonelle Therapie nach weniger als 6 Wochen

- ☐ Infertilität/Kinderwunsch
- ☐ Auf Wunsch der Patientin
- ☐ Zur histologischen Diagnosesicherung bei unklarem Befund
- ☐ Anderes: _____
- ☐ Keine Angabe

17. Wie viel Zeit (in Minuten) Zeit steht Ihnen durchschnittlich zur Verfügung, um eine gemeinsame Therapieentscheidung mit der Patientin zu treffen? _____ Minuten

17.a Erachten Sie diesen Zeitrahmen als ausreichend?

- ☐ Ja
- ☐ Nein
- ☐ Keine Angabe

Multidisziplinäre Versorgung

18. Besteht in Ihrem Setting eine strukturierte interdisziplinäre Zusammenarbeit bei Endometriose?

- ☐ Ja, regelmäßig strukturiert
- ☐ Ja, informell bei Bedarf
- ☐ Nein
- ☐ Weiß nicht
- ☐ Keine Angabe

19. Falls ja: Mit welchen Disziplinen arbeiten Sie im Rahmen der Endometrioseversorgung regelmäßig zusammen? (Mehrfachauswahl)

- ☐ Viszeralchirurgie
- ☐ Urologie
- ☐ Schmerzmedizin
- ☐ Radiologie
- ☐ Gastroenterologie
- ☐ Reproduktionsmedizin
- ☐ Psychotherapie/Psychologie
- ☐ Physiotherapie
- ☐ Ernährungsberatung
- ☐ Komplementärmedizin
- ☐ Sonstige: _____
- ☐ Keine Angabe

20. Wie werden komplexe Fälle (z. B. Darm- oder Blasenbeteiligung) in Ihrer Einrichtung typischerweise versorgt? (Mehrfachauswahl)

- ☐ Behandlung durch eigene gynäkologische Chirurgie
- ☐ In Zusammenarbeit mit spezialisierten chirurgischen Disziplinen (z.B. kolorektale Chirurgie)
- ☐ Überweisung an spezialisiertes Zentrum
- ☐ Kein klar definierter Versorgungspfad
- ☐ Andere: _____
- ☐ Keine Angabe

Fertilität

21. Bei Patientinnen mit Endometriose und Kinderwunsch erfolgt eine fertilitätsbezogene Beratung oder gezielte Weiterleitung.
- ☐ Immer
 - ☐ Meistens
 - ☐ Selten
 - ☐ Nie
 - ☐ Keine Angabe
22. Welches Vorgehen entspricht am ehesten Ihrer bevorzugten Strategie bei Patientinnen mit Endometriose und aktuellem Kinderwunsch?
- ☐ Primär operative Therapie
 - ☐ Primär konservatives Vorgehen
 - ☐ Frühzeitige Überweisung/Einbindung der Reproduktionsmedizin
 - ☐ Kombination aus operativer und reproduktionsmedizinischer Strategie
 - ☐ Kein einheitliches Vorgehen (stark fallabhängig)
 - ☐ Andere: _____
 - ☐ Keine Angabe
23. Erhalten adolozente Patientinnen mit Endometriose in Ihrer Einrichtung eine von erwachsenen Patientinnen abweichende Behandlung oder Weiterleitung?
- ☐ Ja, es erfolgt grundsätzlich eine angepasste Behandlung und/oder spezifische Weiterleitung
 - ☐ Nein, die Behandlung entspricht der bei erwachsenen Patientinnen
 - ☐ Eine spezifische Weiterleitung erfolgt, die Behandlung bleibt jedoch gleich
 - ☐ Es werden keine adolozenten Patientinnen behandelt

Versorgungsstruktur und Rahmenbedingungen

24. Wo sehen Sie strukturelle Hürden für eine leitliniengerechte Diagnostik und Therapie von Endometriose in Ihrem Setting? (Mehrfachauswahl)
- ☐ Lange Wartezeiten
 - ☐ Eingeschränkte Verfügbarkeit spezialisierter Bildgebung
 - ☐ Eingeschränkte OP-Kapazitäten
 - ☐ Fehlende multidisziplinäre Zusammenarbeit
 - ☐ Fehlende klare Überweisungspfade
 - ☐ Mangelnde Kenntnis von Leitlinien
 - ☐ Begrenzte klinische Erfahrung mit komplexen Endometriosefällen
 - ☐ Zeitmangel im klinischen Alltag
 - ☐ Sonstiges: _____
 - ☐ Keine Angabe
25. In welchen Bereichen der Endometrioseversorgung sehen Sie die größten Diskrepanzen zwischen leitliniengerechten Empfehlungen und praktischer Umsetzbarkeit in Wien? (Mehrfachauswahl)
- ☐ Diagnostik (z.B. Bildgebung, Klassifikation)
 - ☐ Medikamentöse Therapie
 - ☐ Operative Therapie
 - ☐ Multidisziplinäre Zusammenarbeit
 - ☐ Shared Decision-Making/Patient:inneninformation
 - ☐ Nachsorge/Langzeitbetreuung
 - ☐ Andere: _____
 - ☐ Keine Angabe

26. Welche Maßnahmen würden aus Ihrer Sicht die Endometrioseversorgung in Wien am stärksten verbessern? (Mehrfachauswahl)
- ☐ Einheitliche Überweisungspfade
 - ☐ Mehr zertifizierte Endometriosezentren
 - ☐ Bessere interdisziplinäre Vernetzung
 - ☐ Mehr Zeit pro Konsultation
 - ☐ Verpflichtende Leitlinienimplementierung
 - ☐ Verbesserte Aus- und Weiterbildung
 - ☐ Andere: _____
 - ☐ Keine Angabe
27. Gibt es aus Ihrer Sicht spezifische Besonderheiten des Versorgungssystems, die die Diagnostik und Therapie von Endometriose beeinflussen?
28. Wo sehen Sie den größten Verbesserungsbedarf an der Endometrioseversorgung in Wien?
29. Gibt es von Ihrer Seite noch Anmerkungen oder Hinweise zur Endometrioseversorgung, die Sie uns gerne mitteilen würden?

A-V Positive Ethics Application



Ref: 042_2026

To whom it may concern,

this is to confirm that the project

Endometriosis care in Austria: A synopsis of international guideline recommendations and assessment of the reality of care in Austria

led by

Lena Grabenhofer, BA, MSc

has been evaluated by the LBG Ethics Committee and received a favourable opinion.

Signed:

Date: 30th.March.2026

A handwritten signature in black ink, appearing to read 'Steph Grohmann', is positioned below the 'Signed:' label.

Dr Steph Grohmann

Senior Program Manager Ethics & Integrity
Ludwig Boltzmann Gesellschaft
Ethics & Diversity Hub



HTA Austria

Austrian Institute for
Health Technology Assessment
GmbH