

HOW CAN WE IMPROVE ENDOMETRIOSIS CARE IN BELGIUM?



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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AGEM	Working Group for Endometriosis in the German Society for Gynaecology and Obstetrics ('Arbeitsgemeinschaft für Endometriose')
AGREE	Appraisal of Guidelines for Research and Evaluation
ART	Assisted reproductive technology
AWMF	Association of the Scientific Medical Societies in Germany ('Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften')
BSGE	British Society for Gynaecological Endoscopy
CNGOF	French College of Obstetricians and Gynecologists ('Collège National des Gynécologues et Obstétriciens Français')
CNS	Clinical nurse specialist
CDM	Chronic disease management
DGGG	German Society of Gynecology and Obstetrics ('Deutsche Gesellschaft für Gynäkologie und Geburtshilfe')
DIE	Deep infiltrating endometriosis
DHMA	Danish Health and Medicines Authority ('Sundhedsstyrelsen')
DNPR	Danish National Patient Registry ('Landspatientregisteret')
DSOG	Danish Society of Obstetrics and Gynaecology ('Dansk Selskab for Obstetrik og Gynækologi')
EEL	European Endometriosis League
ENE	European Network on Endometriosis
ESHRE	European Society of Human Reproduction and Embryology
EVRAS	Compulsory education about relationships, emotional and sexual life in Belgian primary and secondary schools ('Éducation à la Vie relationnelle, Affective et Sexuelle')
FOD VVVL – SPF SPSCAE	Federal Public Service Health, Food Chain Safety and Environment ('Federale overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu'/'Service public fédéral Santé publique, Sécurité de la Chaîne Alimentaire et Environnement')
GDPR	General Data Protection Regulation



GDG	Guideline development group
GP	General practitioner
GRADE	Grading of Recommendations, Assessment, Development and Evaluations
HAS	French National Authority for Health ('Haute Autorité de Santé')
HDA	Health Data Agency
ICD-10	International Classification of Diseases and Related Health Problems, 10th revision
ICD-10-BE	International Classification of Diseases and Related Health Problems, 10th revision, Belgian modification
ICSI	Intracytoplasmic sperm injection
IMA – AIM	Intermutualistic Agency ('Intermutualistisch Agentschap'/'Agence Intermutualiste')
IVF	In vitro fertilization
KCE	Belgian Health Care Knowledge Centre
MDT	Multidisciplinary team meeting
MPC	Multidisciplinary pain centre
MRI	Magnetic Resonance Imaging
MZG – RHM	Hospital discharge dataset ('Minimale Ziekenhuis Gegevens'/'Résumé Hospitalier Minimum')
NENI	Note Requirements Standards for Institutions in the Netherlands ('Nota Eisen Normen voor Instellingen')
NHS	National Health Services (UK)
NICE	National Institute for Health and Care Excellence
NSAID	Non-steroidal anti-inflammatory drugs
NVOG	Dutch Society for Obstetrics and Gynaecology ('Nederlandse Vereniging voor Obstetrie en Gynaecologie')
PREM	Patient reported experience measure
PROM	Patient reported outcome measure
QoL	Quality of life



RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCGP	Royal College of General Practitioners (UK)
RCN	Royal College of Nursing (UK)
RCOG	Royal College of Obstetricians and Gynaecologists (UK)
RIZIV – INAMI	National Institute for Health and Disability Insurance ('Rijksinstituut voor Ziekte- en Invaliditeitsverzekering'/'Institut National d'Assurance Maladie-Invalidité')
RR	Relative risk
SEF	Endometriosis Research Foundation in Germany ('Stiftung Endometriose Forschung')
TCT data	Administrative, clinical and billing hospital data ('Technische Cel voor de verwerking van de gegevens met betrekking tot de ziekenhuizen'/'Cellule Technique de traitement de données relatives aux hôpitaux')
UK	United Kingdom
US	Ultrasound
VVOG	Flemish Society for Obstetrics and Gynaecology ('Vlaamse Vereniging voor Obstetrie en Gynaecologie')
WES	World Endometriosis Society



■ SCIENTIFIC REPORT

1 INTRODUCTION

1.1 Endometriosis, an enigmatic disease

Endometriosis is a chronic, oestrogen-dependent, benign, inflammatory condition characterized by the presence of tissue outside the uterus that resembles endometrium (i.e. the lining of the uterus), mainly on pelvic organs and tissues.¹ Endometriosis can start at a woman's first menstruation and last until menopause, or beyond. Some women with endometriosis don't have any symptoms at all, while others suffer from various symptoms like life-impacting pain during menstruation, sexual intercourse, bowel movements and/or urination, chronic pelvic pain, abdominal bloating, nausea, fatigue, and sometimes depression, anxiety, and infertility.^{2, 3}

The characteristics of endometriosis have already been described in dissertations dating back to the 17th and 18th century.⁴ Yet, anno 2024, the exact cause of endometriosis is still not fully understood.¹

The natural history of the disorder remains uncertain.¹

There continues to be controversy regarding its prevalence and incidence.⁵

There is no international agreement on how to describe and classify endometriosis. Moreover, most classification/staging systems present no or only very little correlation with patient outcomes.⁶

In many affected, there is a long diagnostic delay after onset of symptoms, due to (among others) the nonspecific nature of symptoms, the fear of stigmatization to discuss them, a lack of awareness and because the definitive diagnosis often requires surgery.⁷⁻⁹

There is no cure.¹⁰

Current interventions have unpredictable efficacy, while they carry several side effects and risks.¹¹

Recurrence of symptoms and disease is common even after surgical treatment.¹²



1.2 Endometriosis, on the Belgian policy agenda at last

The last decades, the Belgian scientific community has contributed to research on (among others) the pathogenesis of endometriosis and its risk factors,¹³⁻¹⁶ advancements in detection and diagnostic procedures,^{17, 18} the effectiveness of several therapeutic modalities,¹⁹⁻²¹ the link between endometriosis and subfertility,²²⁻²⁵ as well as the costs associated with endometriosis.^{26, 27} Others focused on the impact of endometriosis on women's physical, mental, and social well-being, their quality of life and work productivity,^{7, 26, 28, 29} or elaborated on the development of tools to assess the patient-centredness of endometriosis care.³⁰⁻³² Several Belgian experts were also involved in the development of international guidelines,^{33, 34} and/or assessed the feasibility of implementing them in clinical practice.³⁵

Only recently, Belgian policy makers have taken up the issue of endometriosis. Preceded by similar initiatives taken by the Federation Wallonia-Brussels (French-speaking community – Fédération Wallonie-Bruxelles),³⁶ the French-speaking Parliament of Brussels (Parlement francophone bruxellois),³⁷ and the Walloon Parliament (Parlement de Wallonie),³⁸ the federal parliament adopted in April 2023 a Resolution on Endometriosis.³⁹ In the Resolution on Endometriosis the Belgian Health Care Knowledge Centre (KCE) is asked (among others) to develop a Belgian clinical practice guideline, to define quality indicators, to perform a thorough evaluation of the current organisation of endometriosis care offered in Belgium (e.g. the distribution, accessibility and quality assessment of multidisciplinary endometriosis reference centres, the relationship between volume and quality of care, the direct and indirect costs of endometriosis (care)), which should also include the identification of the gaps in the care organisation.

1.3 Research questions and objectives

Given the Resolution on Endometriosis approved in the federal parliament, and after careful exploration of the field while taking the strict timeline for this study into account (i.e. five months), the KCE team re-oriented the objectives of the study proposal^a that was originally submitted by one of the patients' associations towards the following research questions:

1. How do affected women experience the physical, emotional, and relational difficulties related to endometriosis and how do they experience the medical encounters in their search for a diagnosis and treatment?
2. What type of endometriosis care is currently offered in the Belgian hospitals? What are the data gaps in the routinely available data?
3. Which initiatives have Belgian hospitals taken to organise endometriosis care in their hospital and/or hospital network?
4. How is endometriosis care organised in a selection of other countries?
5. Which clinical practice guidelines are available, how can they be translated into quality indicators and which challenges can be anticipated when assessing the quality of endometriosis care?

Ultimately, the study is undertaken to inform Belgian policy makers on how the organisation of care for individuals with endometriosis can be improved in Belgium.

^a In the original study proposal KCE was asked to develop a clinical practice guideline for the diagnosis and treatment of endometriosis. But given the availability of the recent (2022) European Society of Human Reproduction

and Embryology (ESHRE) guideline,³³ and the ongoing ADAPTE procedure performed by the Flemish Society for Obstetrics and Gynaecology (VVOG), it was decided that there was only limited added value of producing another guideline. This is further elaborated in chapter 6 of this report.



1.4 Target audience

This report is primarily intended for Belgian policymakers competent for public health and health care, both at the federal and regional level. In the second place, the report will be of interest to healthcare professionals and hospital managers. The report may not satisfy the information needs of individual patients and patients' associations, as they are not our main target audience. Where applicable, we provide links to useful information (e.g. the EHSRE patient leaflet) and to the available patients' associations. We hope that after implementation of the policy recommendations, the organisation of endometriosis care offered in Belgium will improve.

1.5 Disclaimer

The KCE authors acknowledge there are individuals living with endometriosis who are transgender, non-binary, who do not have a uterus, or who do not identify as a woman or with the sex they were assigned at birth. Throughout this report we use the terms 'people/persons/individuals with (suspected) endometriosis' alongside 'women with (suspected) endometriosis', as we do not intend to exclude anybody or discriminate against any group.

1.6 Methodology

To answer the research questions mentioned above, the following methods were applied:

- A review of policy documents, national and international reports, and the international literature, needed to answer research questions 1, 4 and 5 (see chapters 2, 3, 5 and 6, respectively);
- The analysis of women's testimonials, collected beyond the scope of this study by two Belgian patients' associations;
- The analysis of administrative hospital discharge and billing data of a cohort of women admitted in a Belgian hospital in 2016-2020, with as principal or one of the secondary diagnoses endometriosis (see section 4.1);

- The analysis of data collected through a survey which was distributed among the 101 Belgian acute hospitals (see section 4.2);
- The consultation of stakeholders, through:
 - Two face-to-face meetings and where indicated email communication with medical professionals (hereinafter called 'the clinical experts'; see the colophon). Hospitals that indicated in the survey that they had set up an endometriosis clinic, were invited to participate with a maximum of two delegates per hospital. The clinical experts work in academic and non-academic centres, geographically spread over the country, and know the Belgian context very well;
 - Face-to-face consultations with three groups of stakeholders in the final phase: representatives of the federal authorities, patient representatives and representatives of healthcare providers involved in endometriosis care (hereinafter called 'the stakeholders'; see the colophon).

1.7 Structure of the report

In **chapter 2** we provide the reader with some background information on endometriosis, give a concise description of the Belgian health care context and list initiatives that have been taken for other conditions which may serve as an example and/or a backbone for the organisation of care for individuals with endometriosis.

In **chapter 3** we zoom in on women's experiences with the many difficulties related to endometriosis and with their medical encounters in their search for a diagnosis and treatment.

Chapter 4 has two main components. In the first section we focus on the second research question: What type of endometriosis care is currently offered in the Belgian hospitals? The second section is dedicated to the survey among the Belgian hospitals.

Chapter 5 gives an overview of the various initiatives taken in Australia, Denmark, France, Germany, the Netherlands and the UK and their endometriosis care organisation models.



In **chapter 6** we briefly describe the available clinical practice guidelines, how recommendations can be translated into quality indicators and the challenges that can be anticipated when appraising the quality of endometriosis care.

In **chapter 7** a brief discussion of the most important findings is provided, as well as a discussion of the strengths and limitations of the study.

In **chapter 8** we reflect on how the care for individuals with (suspected) endometriosis can be improved and formulate policy recommendations to that end.

2 BACKGROUND

This chapter opens with some background information on the pathogenesis, symptoms, diagnosis and treatment of endometriosis. In addition, the variability in prevalence and incidence estimates is discussed, as well as the impact endometriosis may have on those affected.

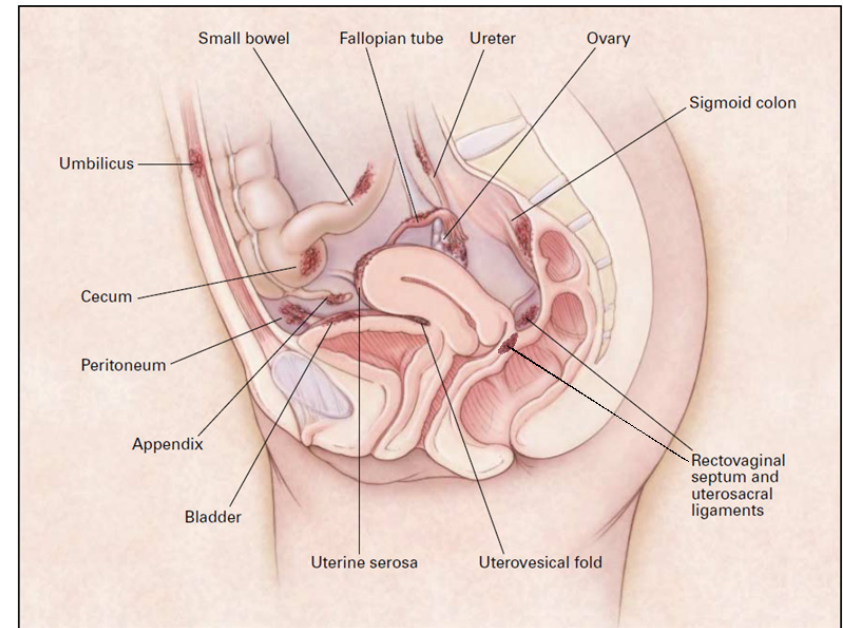
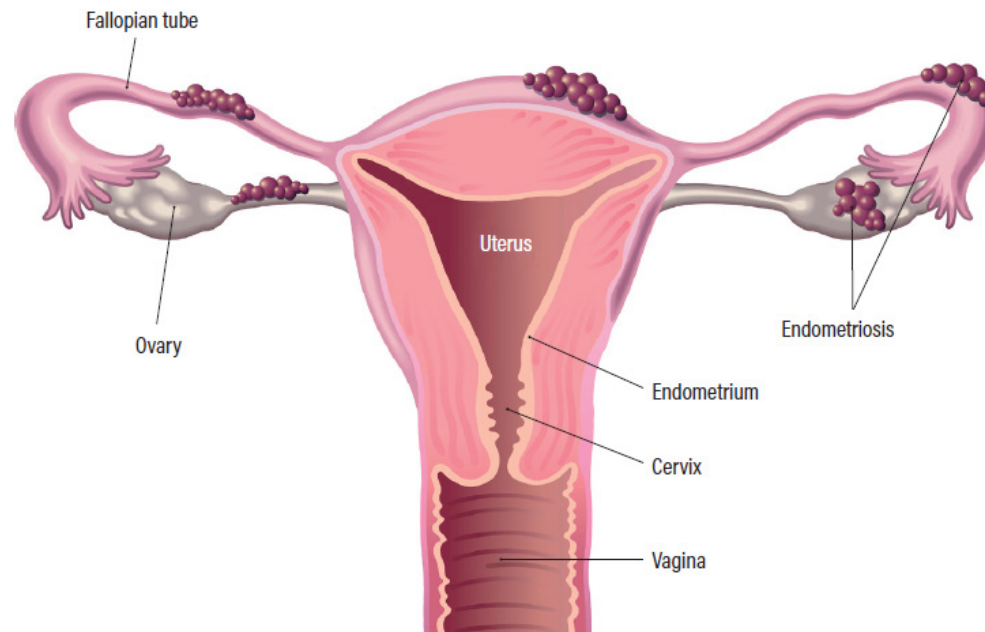
The second part of this chapter starts with a brief introduction on the Belgian healthcare context. It also explores which actions in the health care system have been taken to support, assess or improve the multidisciplinary health care for citizens with other conditions, actions that may be used as an example for the organisation of care for individuals with endometriosis. Finally, the section turns to the endometriosis patients' associations and the initiatives they and others have taken to raise awareness, sensitize, and unite those affected by endometriosis.

2.1 Endometriosis

2.1.1 Introduction

Endometriosis is a common, chronic condition defined by the **presence of endometrium^b-like tissue outside the uterus** (Figure 1). The disease can lead to severe pelvic pain and infertility, may involve multiple organ systems, and can negatively and substantially impact quality of life. Endometriosis is an **oestrogen-dependent** disease and, thus, usually affects reproductive-aged women from the onset of their first period (menarche) through menopause, although symptoms may persist thereafter.³ Endometriosis is a **complex** disease with a **variety of subtypes and clinical presentations**. Its **exact cause** has not yet been established and there is no known way to prevent endometriosis.¹ Limiting the number and/or frequency of menstrual cycles by means of hormonal treatments aims to reduce disease progression,⁴⁰ but its usefulness for the prevention of endometriosis is uncertain.³ As of today, **there is no definite cure for endometriosis**, but there are treatment options for endometriosis-related pain and infertility.¹⁰

^b The endometrium is the inner lining of the uterus which is shed during menstruation.

**Figure 1 – Endometriosis**

Left: schematic overview of the female's internal reproductive system with endometriosis lesions. Right: sagittal section of the pelvis and abdomen with common locations of endometriosis lesions.

Sources: Left: Nadeau et al., 2021⁴¹ (reproduced with permission); Right: Olive et al., 2001⁴² (reproduced with permission)



2.1.2 Origin, location and classification

Although the **cause and natural history** of endometriosis remain **uncertain**, altered hormonal, immunological, and neurological factors are all implicated in symptom development.¹¹ The potential origins of endometriotic lesions include retrograde menstruation and metaplasia of the peritoneal lining.^{43, 44} It is also known that endometriosis can run in families, and twin studies have estimated the heritability of endometriosis as high as 50%, with no specific “endometriosis gene” or consistently identified environmental triggers.^{45, 46} Characteristics associated^c with a greater risk for endometriosis include early age at menarche, short menstrual cycle length, and lean body size, whereas greater parity has been associated with a lower risk of endometriosis.⁴⁷ The majority of endometriotic lesions are located in the **pelvic area** including the ovaries, the peritoneal surfaces as well as the bladder and bowel.¹

Endometriosis presents as a **heterogeneous** disease ranging from superficial or peritoneal disease, cysts in the ovaries (endometrioma), or nodules which penetrate organs surrounding the uterus (deep endometriosis), to extrapelvic lesions in rare cases.^{44d} According to the number of lesions and the depth of infiltration in surrounding organs, different classification/staging systems of endometriosis have been developed.^{49, 50} Importantly, there exists **no general correlation between stage and severity of symptoms**.⁵¹ For example, a woman with stage I or mild endometriosis (few superficial lesions) may have severe pain, infertility, or both; whereas a person with stage IV or severe disease (many deep lesions, dense adhesions) may present with minimal pain.

2.1.3 Symptoms

Key symptoms associated with endometriosis are considered **period-related pain** (dysmenorrhoea) affecting daily activities, **chronic pelvic pain** and a history of **infertility**.² Other symptoms include pain during or after sexual intercourse (dyspareunia), pain during urination, painful bowel movements, and other period-related (cyclical) symptoms.³ It should be underscored that symptoms of endometriosis are **often not specific**, and can mimic those caused by other gynaecological, gastrointestinal, urologic or musculoskeletal conditions (e.g. example of chronic pelvic pain in Box 1).

Box 1 – Chronic pelvic pain and endometriosis

Chronic pelvic pain is often defined as pain perceived to originate from the pelvis, typically lasting more than six months.⁵² It is a challenging problem that affects a significant number of women worldwide.⁵³ Chronic pelvic pain has a **variety of causes** including but not limited to: **endometriosis**, adenomyosis (the presence of endometrium-like tissue in the muscular wall of the uterus), uterine fibroids, ovarian cyst pathology, pelvic inflammatory disease, pelvic adhesions, pelvic floor dysfunction, irritable bowel syndrome, musculoskeletal disorders, and interstitial cystitis.^{54, 55}

Identifying the cause of chronic pelvic pain can be difficult as there are multiple organs in the female pelvis, all of which may present functional symptoms, and multiple pelvic pain disorders often coexist in the same patient.⁵² Individuals with chronic pelvic pain may see multiple clinicians of different specialties who may provide conflicting explanations or management plans, and many cases of chronic pelvic pain remain undiagnosed.⁵⁵

^c Association does not mean causation.

^d For precise terms and definitions for endometriosis, subtypes and anatomical locations, we refer to a consensus based international terminology for endometriosis aiming to facilitate harmonisation in endometriosis research and clinical practice.⁴⁸



Several chronic pelvic pain conditions may share many features whatever the underlying cause, not only in their burden, but also in a similar diagnostic pathway and how they are managed. This KCE-report does not specifically address other causes of pelvic pain, although we acknowledge that several aspects of endometriosis care may also apply to a broader spectrum of chronic pelvic pain conditions.

2.1.4 Diagnosis

When endometriosis is suspected based on symptoms or clinical examination, transvaginal ultrasound and/or MRI is performed to explore a diagnosis, although these techniques cannot always detect (superficial) endometriotic lesions.⁵⁶ **Laparoscopic visualization** of endometriotic lesions with histological assessment via biopsy has traditionally been considered the gold standard for diagnosis,^{2, 44, 56} whereas recent endometriosis guidelines support a **nonsurgical diagnosis** based on **symptoms, physical examination and imaging**.³ Yet, a Cochrane review revealed that none of the imaging methods assessed were able to detect endometriosis with adequate accuracy that they could be recommended to entirely replace surgical assessment.⁵⁶

Endometriosis is a benign disease and, unlike malignant tumors, diagnostic confirmation by surgery is not performed in all patients.⁵⁷ For example, empirical medical treatment (without confirmed diagnosis) might be offered to patients with suspected endometriosis-associated pain before performing diagnostic laparoscopy.⁵⁸ In case of adequate symptom control, surgery can thus be avoided. Nevertheless, it is important to be confident that the underlying diagnostic assumptions are correct, and to identify findings that need more urgent treatment, as **long-term ineffective care can lead to significant morbidity for the patient**.²

The clinical decision to perform (diagnostic) **surgery** depends on many factors, such as the impact of symptoms on a woman's quality of life (QoL), the probability of diagnosis, the estimated extent/location of disease, risk of complications, the experience of the surgeon, the patients' wish to conceive, and the efficacy of empirical treatments.⁵⁷

Currently **no specific diagnostic biomarkers** (e.g. in blood or saliva) to detect or rule out endometriosis are recommended in clinical practice.^{2, 3, 59}

Early results of a saliva-based micro-ribonucleic acid (miRNA) signature are encouraging,⁶⁰ but confirmation in independent and larger studies is required before its clinical use as a diagnostic tool can be advised.

It can be concluded that many factors contribute to the **diagnostic challenge** in endometriosis.⁴⁴ The nonspecific nature of symptoms in addition to the fear of stigmatization of the patient to discuss them, the lack of a diagnostic biomarker, the choice between diagnostic surgery versus empirical treatment, a lack of knowledge and awareness in both patients and medical professionals: all these factors contribute to a **long diagnostic delay of endometriosis** (the time from onset of symptoms to diagnosis), which is often reported to be between six to eight years,⁷⁻⁹ but can take up to 10 years or even longer, especially in women younger than twenty years.^{61, 62}

2.1.5 Treatment

There is **currently no definite cure for endometriosis**. Yet, there are treatment options which focus on **resolving or reducing pain** due to endometriosis or on **improving fertility**. In choosing treatment for endometriosis, it is crucial to consider the patient's predominant symptoms and preferences (e.g. planning to conceive), age, and side-effect profile of the treatment, as well as the extent and location of disease, previous treatment, and costs.⁴⁴ Some patients will require different treatments before finding the appropriate one, and the right treatment may change over time as symptoms and/or preferences change. Some individuals with endometriosis would not require any treatment at all. In case of incidentally diagnosed asymptomatic endometriosis lesions (e.g. during surgery for another indication), it is not routinely recommended in current practice guidelines to treat these lesions.³

There are several medical and surgical treatments for endometriosis-associated pain and infertility. **Medical treatments** include pain medication (analgesics) and hormone treatments, which are often proposed as a first empirical treatment in endometriosis. In patients who are not seeking pregnancy, the oral contraceptive pill is widely used as a first-line treatment for period pain and chronic pelvic pain (see Box 1), with or without presumed endometriosis.



Surgical treatment is an important strategy for the management of endometriosis, with the focus to reduce pain and improve fertility without compromising ovarian function. The latter is an important consideration as ovarian surgery has the risk of diminishing the ovarian reserve and many of the patients are at childbearing age.⁶³ While many surgeries involving limited ovarian and/or superficial endometriosis could be considered relatively straightforward, it is generally accepted that surgical treatment of **severe cases** of endometriosis (particularly disease involving the bowel, bladder, ureters, or extrapelvic structures) requires **multidisciplinary expertise**.^{2, 64} There remain many open questions about the optimal surgical management of endometriosis,⁶⁵ and there is undoubtedly a **need for high quality RCTs** to compare different strategies and surgical techniques.^e

It should be underlined that current medical and surgical treatments for endometriosis are **ineffective for an important proportion of patients**,^{68, 69} while these interventions may result in morbidity through side effects and complications. Furthermore, recurrence of symptoms and disease is common even after surgical treatment,¹² while concerns have been raised that repeat surgery may actually exacerbate symptoms through surgery-induced scarring.¹¹

Beyond medical and surgical treatments, **complementary therapies** (e.g. physiotherapy, exercise, nutrition, psychological interventions, electrotherapy, acupuncture, Chinese medicine) are widely used by patients with endometriosis. At present there is insufficient high-quality evidence to support or refute these interventions. Adequately designed trials are needed to define the potential benefits and potential harms of these complementary interventions.³

^e As a noticeable example, there is little evidence to demonstrate whether surgical removal of isolated superficial endometriosis during diagnostic laparoscopy improves pain symptoms and quality of life.⁶⁶ The main objective of an ongoing multi-centre RCT (ESPrIT2) in the UK, funded by the National Institute for Health Research (NIHR), is to determine whether surgical

2.1.6 Prevalence and incidence

The **exact prevalence and incidence of endometriosis in Belgium is not known**. These data are anticipated, as in the current health interview survey^f respondents are asked for the first time whether they have been diagnosed with endometriosis.

In the international literature, **prevalence and incidence estimates** for the overall population **vary**. An oft-cited review on endometriosis from 1997 reported a prevalence of 10% of the female population, based mostly on laparoscopic diagnosis in surgical cohorts from the 1980s.⁷⁰ This figure has become widespread as reported prevalence in various sources.^{2, 10, 71} This estimate was however likely affected by selection bias, as patients undergoing laparoscopy are expected to have a higher underlying risk of endometriosis than the general population.

In more recent studies, prevalence estimates for endometriosis in post-menarche, pre-menopausal women vary between 0.7% and 18.9%.⁷²⁻⁷⁸ This variation is mainly due to **differences in study design**. In population-based integrated information system studies, which typically use diagnostic codes from health insurance data or hospital discharge records, the prevalence varies from 0.7% to 2.2%.^{72, 73, 76} Studies using women's self-report show prevalence estimates of 2.2% to 8%,^{72, 76} whereas studies using radiological or surgical diagnosis in convenience cohorts show prevalence estimates ranging from 1.1% to 18.9%.^{76, 77} Prevalence estimates based on diagnostic codes are an underestimation of the true burden, as not all women with symptomatic endometriosis will have a medical diagnosis or the diagnosis might not have been reported. On the other hand, prevalence estimates based on (self-selecting) patient surveys or radiological/surgical diagnosis in convenience samples of women may offer overestimations, as these samples are not likely to be representative of the whole population of menstruating individuals. Moreover, as some studies using laparoscopic

removal of these superficial lesions is of benefit, exacerbates symptoms, or even causes harm.⁶⁷ The importance of such research should be emphasized as it has the potential to change clinical management of endometriosis patients worldwide.

^f The fieldwork for the 2023 health interview survey will last at least until the end of June 2024; the first data are expected at the end of 2024/start of 2025.



diagnosis also found a high prevalence of low-stage endometriosis in asymptomatic women,⁷⁴ not all surgically confirmed endometriosis constitutes symptomatic endometriosis necessitating medical and/or surgical care.

A recent **meta-analysis** including all study types found a pooled estimate of 4.4%,⁷⁶ Another meta-analysis reported a pooled prevalence estimate of 1% for population-based integrated information system studies, 5% for studies using self-reported data and 4% for other study designs.⁷²

Incidence estimates also vary, ranging from 1.12 per 1 000 person-years to 6 per 1 000 person-years.^{75, 78} The highest incidence is typically noted in women aged 30-40 years.^{73, 75, 78}

The Australian Longitudinal Study on Women's Health (ALSWH) is a large population-based prospective cohort study, combining survey data (from 8 surveys between 2000 and 2022) with administrative health data (Medicare Benefits Schedule and Pharmaceutical Benefits Scheme).⁷⁹ This study reported a **cumulative incidence** (lifetime risk of diagnosis of endometriosis by a certain age) of surgically confirmed endometriosis in 7.6% of women by age 44-49, and of clinically suspected endometriosis in an additional 6.6% of women by the same age. A younger cohort appeared to have higher cumulative incidence rates, which may reflect increased awareness and/or diagnosis.⁷⁹

As an exploratory exercise, we calculated an estimate for the prevalence of endometriosis in Belgian women aged 16-49 years, using the cumulative incidence data (stratified by 3-year age bands) from this study.⁸⁰ We used data from Statbel, the Belgian statistical office,⁸¹ to obtain the 2023 Belgian population structure. Assuming cumulative incidence numbers for both confirmed and suspected endometriosis from the 1973-1978 Australian cohort for Belgian women aged 32-49 years of age and the cumulative incidence numbers from the 1989-1985 Australian cohort for Belgian women aged 16-31, we obtain an estimated **230 808 women affected by**

endometriosis in Belgium, which amounts to 3.9% of the total female population and 9.3% of the female population aged 16-49 years of age. Of course this estimate should be interpreted with caution, as the assumption that the cumulative incidences from the Australian population are also valid for our population may not be justified.

2.1.7 Burden of disease

Endometriosis can negatively impact **many aspects** of an individual's life (see also chapter 3), including physical functioning, mental health and emotional wellbeing, sexual and social relationships, family functioning, as well as education and work.⁸² Endometriosis symptoms, and specifically pain, have a substantial impact on daily life and **physical functioning**.^{7, 28, 83} Individuals who suffer from endometriosis report high levels of **mental health** symptoms such as depression and anxiety,⁸⁴ and the disease has a significant effect on **sexuality** and relationships.⁸⁵

Adolescents with endometriosis report worse quality of life (QoL) compared to their unaffected peers, with impairment in the ability to attend school, participate in social activities, and exercise.⁸⁶ The **negative educational impact** of endometriosis in both adolescents and adults are attributed to endometriosis-associated pain, which leads to interference with school and work.⁸² In addition, there is significant evidence demonstrating the substantial **financial burden** of endometriosis on affected individuals and on society in general, as observed by both direct (including in and outpatient treatment, surgery, and prescription costs) and indirect (including absenteeism and presenteeism) costs.^{7, 26, 87, 88} A study among 134 endometriosis patients seen in a Belgian tertiary care centre in 2009, estimated the average annual total costs⁹ of endometriosis at nearly €10 000, mainly due to productivity losses.⁸⁹ Adjusted for inflation based on the Organisation for Economic Co-operation and Development (OECD) deflator index for Belgium,⁹⁰ this corresponds to €13 529.41 (2022). The

⁹ These costs from a societal perspective included direct healthcare costs, direct non-healthcare costs (transportation costs to healthcare providers and costs from receiving additional support with household activities), and indirect non-healthcare costs (productivity loss related to work impairment).⁸⁹



same study reported a mean quality-adjusted life years (QALY)^h of 0.82 over a 1-year period for those with endometriosis-associated symptoms, which is consistent with the results from a multi-centre study across ten countries (the WERF EndoCost study).²⁶

Key points:

- **Endometriosis is a complex and heterogeneous disease with a variety of subtypes and clinical presentations;**
- **Many factors contribute to a long diagnostic delay, often reported to be between six to eight years;**
- **As of today there is no definite cure for endometriosis;**
- **There are medical and surgical treatment options for endometriosis-related pain and infertility, with variable success rates;**
- **Exact prevalence and incidence of endometriosis in Belgium is not known;**
- **In the international literature, prevalence and incidence estimates for the overall population vary;**
- **The disease can negatively impact many aspects of an individual's life, including physical functioning, fertility, mental health and emotional wellbeing, sexual and social relationships, family functioning, as well as education and work.**

2.2 The Belgian context

2.2.1 Introduction

Over the last decades, Belgium evolved into a federal state, composed of communities and regions. Through six state reforms, the competences for a broad range of matters, including health, were transferred (in part) to the federated entities. This resulted in a complex institutional structure with one federal and seven regional ministers being responsible for health.⁹¹ So-called 'inter-ministerial conferences' are organised to coordinate policies between the different levels.

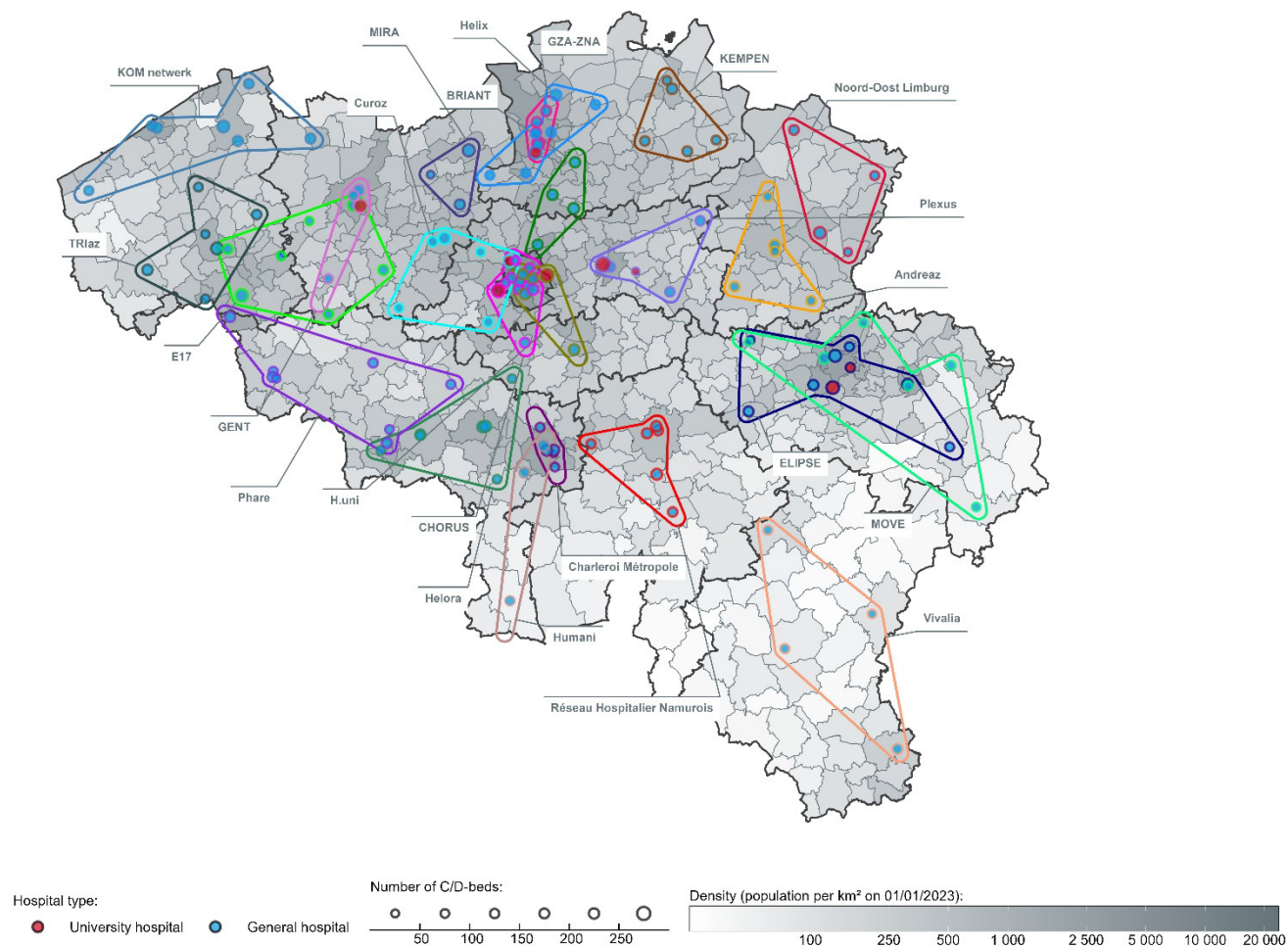
The Belgian healthcare system is based on a compulsory national health insurance, which provides coverage for a large range of services to nearly the entire population.⁹² The provision of care is predominantly based on a fee-for-service payment. The fee schedule (called the 'nomenclature'), specifies the official fees and cost-sharing mechanisms.⁹² These are settled in agreements (for physicians and dentists) and conventions (for other health care providers), which are negotiated annually or every two years between representatives of sickness funds and health care providers. In general, patients' co-payments are a proportion of the national fee, but for consultations at a GP's office (since December 2011) and for consultations at a medical specialist's office (January 2015), the co-payment is now a fixed amount, which is not indexed.⁹²

Following the international trend towards hospital consolidation and collaboration, an action plan to reform the hospital landscape was launched in April 2015. As a result, locoregional clinical hospital networks were created with their own governance structures (Figure 2). The locoregional hospital networks offer particularly a framework in which hospitals can collaborate.⁹³ In the Royal Decree of 23 November 2022, the locoregional and supra-regional care assignments have been defined.⁹⁴ A **locoregional care assignment** must be offered in every locoregional clinical hospital network, while a **supra-regional care assignment** cannot be offered in every locoregional clinical hospital network.

^h QALY is measured on a scale of 0 to 1, where 0 and 1 correspond to the worst and best possible health state, respectively.



Figure 2 – Distribution of the Belgian acute hospitals within the locoregional hospital networks



Source: Federal Public Service Health, Food Chain Safety and Environment; situation of 31 December 2023.



So far, the care for individuals with endometriosis has not been structurally organised in Belgium. Still several initiatives have been taken for other pathologies and conditions (e.g. cancer, fertility problems, chronic pain) to improve the organisation of and/or access to care, ensure the multidisciplinary approach, or the assessment of the quality of the care offered. These initiatives are briefly described in the following sections as they may serve as an example and/or a backbone for the organisation of care for individuals with endometriosis and its quality assessment. In the last section, we provide a (non-exhaustive) overview of initiatives taken by patients' associations and others.

2.2.2 Rehabilitation conventions

In the Belgian health care system, agreements with the National Institute for Health and Disability Insurance (RIZIV – INAMI), also known as '**RIZIV – INAMI conventions**' are a **means of financing care which primarily applies to multidisciplinary care**, particularly in the rehabilitation sector.⁹⁵ The agreements define at least partly the activities of the centres and their financing. During the past decennia RIZIV – INAMI conventionsⁱ have been developed for a large heterogeneity of chronic and/or complex conditions, transcending the field of rehabilitation (e.g. diabetes, dementia, respiratory disease, rare metabolic diseases, genital mutilation; the list of conventions can be found in Appendix 1.6). In addition to condition-based agreements, agreements have been made with specific (rehabilitation) centres (e.g. unwanted pregnancies, care units for chronically ill children, cardiorespiratory monitoring of babies) and for the reimbursement of specific costs (e.g. occupational therapy, travel expenses of patients in a wheelchair and of children in a rehabilitation centre).⁹⁵

Most conventions, especially the older ones, have an open-ended system, but there is a trend towards more closed envelopes to keep control of the expenses. In some conventions a closed envelope is allocated to a health care centre, sometimes the envelope encompasses all centres in the convention. Providers are mostly salaried, although exceptionally providers

are allowed to work based on a fee-for-service. Each centre has an individual agreement with the RIZIV – INAMI that stipulates the exact price of a treatment.⁹⁵

2.2.3 Care programmes

Several care programmes have been introduced in the Belgian healthcare system to provide patients with appropriate care at the right time.⁹⁶ Care programmes work in a **multidisciplinary and transversal** way, i.e. multiple healthcare providers and different disciplines work together, across hospital boundaries and between healthcare facilities. In contrast to the RIZIV – INAMI conventions, the care programmes are coordinated (and funded) by the Federal Public Service Health Food Chain Safety and Environment.

Current care programmes are specialised care programmes. They focus on groups of patients with a specific pathology (e.g. cardiac problems, oncology) or on an organisational or functional aspect of a care facility (e.g. emergency care).⁹⁶

For a care facility to offer a particular care programme, it must meet a number of licensing standards, which may relate to e.g. the required infrastructure, the required medical and non-medical staffing and expertise, the minimum activity level.⁹⁶

2.2.3.1 Care programme for reproductive medicine

Since 1999, there are **two types of care programmes (centres) for reproductive medicine**, A and B.⁹⁷ The main difference between both is that only B centres are allowed to create and store embryos in vitro, and thus to perform an entire assisted reproductive technology (ART) cycle. Therefore, A centres have to transport their retrieved gametes to a B centre for in vitro fertilisation and for gamete and embryo cryopreservation. A and B centres are coordinated by a specialist in gynaecology-obstetrics with at least three years' experience in reproductive medicine, who works

ⁱ Following the 6th Reformation of the State, some of the RIZIV – INAMI conventions have been transferred to the communities in 2018.⁹⁵

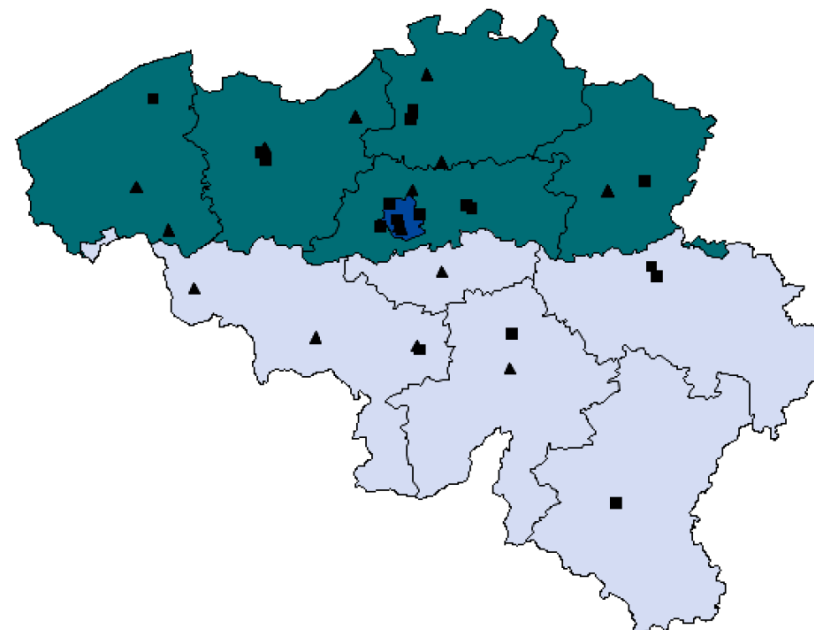


exclusively at the hospital. The licensing standards^j further stipulate that A centres should also have a medical specialist in reproductive endocrinology available in the hospital. The other major licensing standards are listed in Box 12 (Appendix 1.1).

Programming standards and geographical distribution

The Royal Decree of 15 February 1999 limits the number of centres to one A centre per 700 000 inhabitants.⁹⁸ For university hospitals, the number of B centres is limited to one B centre per faculty of medicine with a complete curriculum^k. The number of non-university B centres is restricted to one per province^{l,98}. In September 2023, there were **sixteen A and eighteen B centres** for reproductive medicine^m (Table 15, Figure 3).

Figure 3 – Geographical distribution of centres for reproductive medicine in Belgium



16 A centres (▲) and 18 B centres (■)

Source: College of Physicians Reproductive Medicine, 2021⁹⁹

^j Since the sixth state reform, the regions are competent to change recognition criteria. Since then, the federal level is only competent for organic recognition criteria for hospitals, in addition to the programming and the financing of operating costs.

^k If a faculty of medicine with full curriculum has not organised a reproductive medicine care programme B on its own, but has organised the care

programme in collaboration with a non-university hospital, that programme may be recognised if it meets the relevant recognition criteria.⁹⁸

^l The Brussels Capital Region is on the same footing as a province.⁹⁸
^m Additionally, there are a few collaboration agreements ('associatie'/'association'; n = 5) between hospitals without a reproductive medicine care program and a number of A and B centres.



In the Royal Decree of 23 November 2022, the care programme reproductive medicine A is qualified as a locoregional care assignment, whereas the care programme reproductive medicine B is qualified as a supra-regional care assignment.⁹⁴

Financing

In contrast to the oncological care programmes, for which dedicated financing for paramedical staff is provided (e.g. data managers, oncological nurses, psychologists, based on the number of recorded multidisciplinary team meetings), there is no additional funding provided in the Budget of Financial Meansⁿ for reproductive medicine care programmes. (*Federal Public Service Health, Food Chain Safety and Environment, personal communication*)

Evaluation

External evaluations of the centres for reproductive medicine are performed on a yearly basis by the Belgian Register for Assisted Procreation^o (Belrap, a legally registered non-profit organization). Their national report provides an overall picture of the quality and success of ART treatments performed in Belgium.⁹⁹

2.2.4 Pain policy in Belgian hospitals

Since July 2013, every acute hospital in Belgium receives dedicated funding for the installation of a **multidisciplinary algology team**^p, i.e. a physician-coordinator, and nursing as well as psychological support.¹⁰² Their main task is to sensitize and train peer healthcare providers from all hospital departments on the detection and management of pain.

In addition, thirty-five hospitals receive a fixed lump sum^q for the development of a **multidisciplinary centre for the treatment of chronic pain** (MPC; Table 16).¹⁰² These centres do not only have to offer care to patients with chronic pain, they also have to develop 'knowledge networks' with the algology teams of the hospitals that do not have a MPC, so that expertise on the prevention and early detection of chronic pain can be shared and that the smooth referral of these patients is ensured. MPCs have to report on an annual basis. The agreement with Federal Public Service Health, Food Chain Safety and Environment is renewable on an annual basis.

ⁿ Each year the national hospital budget or Budget of Financial Means (BFM) is defined by Royal Decree. It is a closed-end budget covering non-medical activities, such as the services for accommodation, accident and emergency services, and nursing activities.¹⁰⁰

^o In the future, mandatory registration of activities for medically assisted reproduction (IVF and non-IVF) will be done on the platform Healthdata.be (see section 1.2.6), while Belrap will continue the data processing.¹⁰¹

^p The funding is in proportion to the number of licensed beds per hospital.

^q The funding (€271 000 per year, which is not subject to indexation) is provided by the Federal Public Service Health, Food Chain Safety and Environment ('Federale overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu'/'Service public fédéral Santé publique, Sécurité de la Chaîne Alimentaire et Environnement'). (*Federal Public Service Health, Food Chain Safety and Environment, personal communication*)



2.2.5 Measures for citizens with a chronic condition

The last decade, there were several initiatives to improve the quality of care for Belgian citizens with a chronic condition^r. In this chapter we focus on three.

2.2.5.1 Care trajectories

Care trajectories ('zorgtraject' / 'trajet de soins') were developed for patients with diabetes and chronic renal insufficiency 'to improve the cooperation between patients, their GP, specialists and other involved health care providers'.¹⁰³ This resulted in improved follow-up of the care processes and patient satisfaction, yet, the participation rate was suboptimal due to a lack of awareness on their existence.¹⁰⁴

2.2.5.2 Statute chronic condition

The statute chronic condition, which is primarily a financial protection system, has been set up to facilitate access to care for citizens with a chronic condition.⁹² It entails a reduction of the cap beyond which co-payments are covered by the sickness funds (Box 2).

Box 2 – The third-party payment system and the system of maximum co-payments

Initially, the large majority of Belgian citizens had to pay the fees for medical services in advance and then claim reimbursement from their sickness fund (to avoid over-consumption and promote the responsible use of public funds). The **third-party payment system** (where sickness funds pay their share directly to the health care provider) was limited to the purchase of prescribed medicines and hospital/residential care. In recent years, the third-party payment system has been gradually extended, first to vulnerable groups and patients with a chronic condition,⁹² but nowadays also to the general public.¹⁰⁵

If the medical costs that a patient or family has to pay after being covered by the compulsory health insurance, reach a maximum amount (a 'cap'^s), the **system of maximum co-payments ('maximumfactuur' (MAF)/'maximum à facturer' (MàF)** is applied. It entails that any co-payments beyond this cap are reimbursed by the sickness funds.¹⁰⁶ There are four different systems, each with their own calculation of the cap.⁹² One of them targets patients with a chronic condition (cf. infra).¹⁰⁶

The statute is granted automatically in certain cases, or on the basis of a medical certificate to be delivered to the sickness fund.¹⁰⁷ In 2020, 12.1% of Belgians were entitled to the chronic condition statute; 12.9% in the Walloon region, 12.2% in the Flemish region, and 9.4% in Brussels. The regional differences have been in part attributed to differences in age distribution. In all regions women are overrepresented.¹⁰⁸

^r An exhaustive list of all initiatives can be found on the website of RIZIV-INAMI: <https://www.inami.fgov.be/nl/themas/kost-terugbetaling/ziekten/chronische-ziekten/Paginas/default.aspx>; <https://www.inami.fgov.be/fr/themes/cout-remboursement/maladies/chroniques/Pages/default.aspx>.

^s The following medical costs are included to calculate the maximum amount, and are reimbursed if the cap is exceeded: co-payments for

services provided by physicians, dentists, nurses, physiotherapists and other healthcare providers; co-payments for medicines in categories A, B and C (Cs and Cx not included) and for magistral preparations; co-payments for technical services (e.g. X-rays, lab tests); certain costs in case of hospital admission, such as the personal share of the hospital day price; delivery costs for medical implants and devices. Yet, other costs, for example supplements which are charged on top of fees or daily rates for long-term (i.e. more than one year) stays in psychiatric hospitals are not included.⁹²

**Box 3 – Who is eligible for the RIZIV – INAMI chronic condition statute?**

The statute chronic condition is granted to:¹⁰⁷

- Residents with medical care expenses (i.e. part covered by the health insurance and co-payment) of at least € 365.18 per trimester (2023^t), for eight consecutive trimesters;
- Residents who are granted the lump sum for chronically ill patients (i.e. who are in a situation of dependency and who have paid a total amount of co-payments of at least €450.00 (€365.00 for people with an increased allowance) during the current and previous calendar year);
- Residents with a rare or orphan disease (i.e. a disease that affects no more than 1 in 2 000 people), who have medical care expenses (i.e. part covered by the health insurance and co-payment) of at least € 365.18 per trimester (2023^t) for eight consecutive trimesters.

For the first two groups the statute is granted for two years, and can then be extended from year to year. For residents with rare or orphan diseases, the statute is granted for five renewable years.

Source: RIZIV – INAMI¹⁰⁷

Of note, a recent assessment of the health system performance focused on the care for people living with chronic conditions, revealed that only 31.5% of the citizens self-reporting a chronic disease and 39.2% of those with a multimorbid state^u, actually benefit from the RIZIV – INAMI chronic condition statute.¹⁰⁸ This result is (in part) due to the financial criteria on which eligibility for the statute is based. Patients affected by a chronic disease but

without high medical expenses (< €365.18 per trimester) are not entitled to the current chronic condition statute. Secondly, patients with irregular medical expenses will have difficulties to attain the chronic condition statute, because the current statute requires eight consecutive quarters of high expenses. The chronic condition statute is a financial protection system and, as a consequence, being entitled to this status depends on the long-lasting cost of a chronic disease and therefore not on living with a chronic disease in itself.¹⁰⁸

2.2.5.3 Reimbursement for paracetamol

In Belgium drugs are classified in several reimbursement categories. The reimbursement category of a pharmaceutical specialty depends on its medical therapeutic interest and the 'necessary' character of the specialty. The category indicates the extent to which the health insurance provides reimbursement and thus the patients' share.¹⁰⁹

'Basic analgesics', for instance, are classified in Category D, for which there is no reimbursement (hence the patient has to pay the full price). Yet, patients with chronic pain can obtain lifelong 75% reimbursement for large packages of paracetamol, upon approval of a request submitted by their physician to their sickness fund.¹¹⁰

^t The amount is each year subject to indexation.

^u For the definition of multimorbid state, ten diseases were considered: asthma, chronic obstructive pulmonary disease (COPD), acute myocardial infarction (AMI) and consequences, coronary heart disease, other serious heart disease, hypertension, osteoarthritis, arthritis, cancer and diabetes. In the final construction of the definition, asthma and COPD were grouped as 'chronic lung disease'; AMI and consequences, coronary heart disease and

other serious heart disease were taken together as 'serious heart disease'; and osteoarthritis and arthritis (two different questions) were also pooled. This resulted in six diseases or disease groups: chronic lung disease, serious heart disease, diabetes, osteoarthritis/arthritis, hypertension and cancer. Multimorbidity was defined as having at least two from those six, implying that people reporting only two diseases from the same 'disease group' were not considered as multimorbid.



2.2.6 Multidisciplinary team meetings (MDT)

The best known multidisciplinary team meetings (MDT) in Belgium are those in oncological care (also known as 'Multidisciplinair Oncologisch Consult (MOC)' / 'Concertations Oncologiques Multidisciplinaires (COM)'), which were introduced in 2003 (Box 4).¹¹¹ The main purpose of these MDT meetings is to develop a strategic plan for the diagnosis, treatment and follow-up and to discuss the overall care of an individual patient with a malignancy.

Box 4 – Multidisciplinary team meetings (MDT) in oncology – main outlines

In oncology, there are **three different MDT meeting types**: the 'first MDT' meeting, which can be billed once at the diagnostic phase, the 'follow-up MDT' meeting which can be billed 'if required by the evolution of the disease and treatment plan' (and gets a lower reimbursement (K50 instead of K80)), and 'a second advice MDT' meeting (also known as 'supplementary MDT' meeting), which can be billed by a hospital where the patient is referred to.

The **minimum number of participants** is four physicians from different specialties, at least one of whom is specialist in oncology; the coordinator is one of these four specialists. Remuneration for attendance is restricted to a maximum of four specialists, and a dedicated remuneration is provided for the patient's GP.

In addition, **remuneration** is provided for one of the specialists attending the MDT meeting, as well as for the GP, to **discuss in depth** the diagnosis, the proposed additional investigations, and the treatment plan **with the patient**.

For each patient discussed during the MDT meeting, the coordinator is legally bound to lay down a **report** and to **complete a registration form**, which has to be submitted to the Cancer Registry.

Based on the number of MDTs recorded, hospitals receive **additional funding for supporting para-medical staff** through the Budget of Financial Means¹¹². For every 250 recorded MDTs, hospitals will receive funding for a full-time psychologist and full-time nurse, a half-time social worker, and 1/4 FTE for a data manager.

Source: Vrijens et al., 2015;¹¹¹ RIZIV – INAMI, 2023.¹¹²

2.2.7 Registries

A large number of patient registries and databases with health data have been established in Belgium over the past decades.¹¹³ Among them, there are several disease-specific registries, such as the Belgian Cancer Registry (BCR), the Belgian Tuberculosis Registry, the Belgian Diabetes Registry (BDR), and the Belgian Cystic Fibrosis registry (BCFR).

Within the frame of the national eHealth action plan 2013-2018, the Scientific Institute of Public Health (Sciensano since 2018) was charged in 2012 with centralizing and improving clinical registries in a new platform, named Healthdata.be. The Healthdata.be platform ensures that the registration and preservation of health data are standardised and uniform. The data collected in Healthdata.be are available only to authorised researchers.

One aspect of the Healthdata.be mission is to provide a publicly accessible web application with a central inventory of existing databases with health and health care related data. This overview can be consulted through the FAIR^v portal (<https://fair.healthdata.be>), which acts as a metadata portal and provides, among others, information on the legal basis and design of the included databases.¹¹⁴ This platform currently provides information on 283 databases including 213 registries (October 2023), however, not all existing

^v FAIR (Findable, Accessible, Interoperable and Re-usable) principles. A more elaborate metadata catalogue is planned as part of the mission of the

Belgian Health Data Agency (<http://www.ejustice.just.fgov.be/eli/wet/2023/03/14/2023041135/justel>), but is currently not yet available.¹¹⁴



disease registries are included in this portal. A (non-exhaustive^w) list of disease-specific registries which aim to measure or improve the quality of care, and which could serve as an example for an endometriosis registry is provided in Table 17 (Appendix 1.4).

Organisational framework & funding

Several national disease registries are managed by Sciensano and funded publicly through the Institute for Health and Disability Insurance (RIZIV - INAMI). Other funding bodies include private non-profit funding bodies (e.g. King Baudouin Foundation) and private for-profit funding bodies (e.g. pharmaceutical companies).

The disease registries are often embedded within the framework of a convention (see section 2.2.2). Under these circumstances, the registration of data in the registry is one of the obligatory tasks of the reference centres. The centres receive from Sciensano a feedback report benchmarking the results of their centre with those of the other centres, allowing quality improvement initiatives.

On 14 March 2023, the establishment and organisation of a federal Health Data Agency (HDA) has been approved by law.¹¹⁵ The HDA aims, among other tasks, to streamline health data access requests, to facilitate the standardisation and “FAIRification” of data, to provide a national data catalogue, and to be the national contact point for secondary use of health data.¹¹⁶

Privacy and ethics

First of all, all registries for health (care) data must follow the rules and safeguards stipulated in the EU General Data Protection Regulation (GDPR) law which went into effect on 25 May 2018.¹¹⁷ The Belgian Data Protection Authority (‘Gegevensbeschermingsautoriteit’ – ‘L’Autorité de protection des données’) is the competent authority to verify GDPR compliance as stipulated in the Belgian Law of 30 July 2018 on the protection of natural persons with regard to the processing of personal data.¹¹⁸

In addition, platforms like Healthdata.be require that all clinical registries that wish to use its platform, receive an a priori deliberation by the Information Security Committee (IVC-CSI)^x.¹¹³ Finally, data collection and participation in the registry needs the approval of the local ethics committee of each participating centre, and often^y, informed consent has to be obtained from the patients and/or the parents or legal guardian.

2.2.8 Initiatives^z taken by patients’ associations and others on endometriosis

Currently there are **three patients’ associations** in Belgium which are **dedicated to endometriosis**: Endométrie Belgique a.s.b.l.^{aa}, Toi Mon Endo a.s.b.l.^{bb} and Behind Endo (stories) vzw^{cc}. They raise awareness and break the silence surrounding endometriosis (e.g. by public awareness campaigns, social media initiatives, education projects in schools) and bring people affected by endometriosis together. In addition, they offer social support to those affected and their partners, and help patients during their care path so that the delay in diagnosis can be reduced. In Table 18 a (non-exhaustive) list of initiatives taken by Belgian patients’ associations in Belgium is provided (Appendix 1.7). Beyond the patients’ associations, other

^w This is not an exhaustive overview of disease-specific registries in Belgium as for instance not all registries on rare diseases are included.

^x More information on security and privacy of the platform is available from: <https://healthdata.sciensano.be/en/information-security-privacy>; IVC-CSI see also <https://dt.bosa.be/nl/ivc>

^y For registries established in law like the Belgian Cancer Registry, this is not always the case.

^z The authors of this report acknowledge that the list of initiatives mentioned in this section is not exhaustive.

^{aa} <https://endositebelgique.wixsite.com/endobe>

^{bb} <https://toimonendo.com/>

^{cc} <https://behindendo.be/>; Behind Endo (stories) vzw works together with the platform Endo Awareness BE-NL (<https://endoawarenessbenl.wordpress.com/infomateriaal/>)



initiatives have been taken by women with endometriosis to raise awareness about their condition. The documentary MyEndo^{dd}, for instance, illustrates the struggle with the challenges faced by many chronic endometriosis patients. Based on photo shoots organised during patient gatherings, Endo.Insideout^{ee} sets up a photo exhibition with portraits of endometriosis patients. But also podcasts^{ff} have been developed to break the taboos on endometriosis.

There were also more **local initiatives**, like for instance the pilot project in Liège to set up a first-line unit dedicated to chronic pelvic pain, together with Infor Femmes Liège.¹¹⁹ The province of Liège has developed an awareness campaign, in collaboration with two hospitals (CHR Citadelle and Clinique CHC Montlégia).¹²⁰

It's only quite recently that Belgian **politicians and policy makers** have taken up the issue of endometriosis, following calls for action from patient associations,¹²¹ and the increased attention given to the disease in other countries.^{71, 122-125} For instance, in 2021 the government of the Federation Brussels Wallonia (French-speaking community – Fédération Wallonie-Bruxelles) launched in collaboration with one of the non-profit patients' associations (i.e. Toi Mon Endo a.s.b.l) a pilot project to raise awareness on endometriosis among the general population and future health professionals.³⁶ In February 2022, the French-speaking Parliament of Brussels (Parlement francophone bruxellois) adopted a resolution on better care and awareness on endometriosis.³⁷ Also in spring 2022, the Walloon Parliament (Parlement de Wallonie) adopted a resolution to improve awareness and research for better endometriosis care.³⁸ As in Brussels, the Walloon resolution aims to strengthen cooperation between the various policy levels in order to improve the management of endometriosis and to promote awareness among the general public, in particular through family

planning centres and courses in relationships, emotions and sexuality⁹⁹ for youngsters, future professionals during their training and the various players in the working world. The resolution also aims to mobilise financial resources for research. In June 2023, a motion of resolution^{hh} was submitted to the Flemish parliament to develop a Flemish endometriosis plan also proposed based on several existing demands from the Flemish community on endometriosis: better education for health professionals to improve their knowledge of the disease, the recognition of symptoms associated with endometriosis and its (long-term) consequences (e.g. fertility). Furthermore, the motion of resolution proposed to reduce the diagnostic delay and increase the awareness of endometriosis in the general population (e.g. school education, and awareness campaigns).¹²⁷

At the federal level, the Secretary of State for Gender Equality, Equal Opportunities and Diversity launched a call for projects on gender issues in 2022, 'As long as it takes'; one of the themes was endometriosis.¹²⁸ The project 'L'endomètre en santé' developed by the 'Centre de Planning familial Infor-Femmes Liège' was funded through this call.¹¹⁹

^{dd} <https://myendo.eu/nl/>

^{ee} <https://www.instagram.com/endo.insideout/>

^{ff} <https://www.rtf.be/article/un-podcast-pour-briser-les-tabous-de-l-endometriose-10699737>;

^{gg} l'Education à la Vie Relationnelle, Affective & Sexuelle (EVRAS); the EVRAS website offers several references on endometriosis for parents and EVRAS professionals.¹²⁶

^{hh} In the motion of resolution a plea was made in favour of gender-sensitive care, better training for health professionals to improve their knowledge of the disease, the recognition of symptoms associated with endometriosis and its (long-term) consequences (e.g. fertility) and increased awareness of endometriosis in the general population so that the diagnostic delay can be reduced.¹²⁷



3 PATIENT PERSPECTIVES ON ENDOMETRIOSIS

3.1 Introduction

Endometriosis has a profound impact on women's quality of life because of its' symptomatology, delayed diagnosis, limited treatment options, chronic character, risk of infertility and emotional impact. Individuals with endometriosis experience a wide array of symptoms. We explored women's experiences with the extensive physical, emotional, relational difficulties related to endometriosis and with their medical encounters in their search for a diagnosis and treatment.

3.2 Methodology

In order to learn about women's experiences with endometriosis, we used two sources of information. Firstly, we searched the international literature. We solicited the body of knowledge built by other researchers to build a conceptual framework with the themes re-emerging throughout the literature. Secondly, we analysed written testimonials of women with endometriosis living in Belgium. The latter analysis consisted of identifying:

- The themes represented in the conceptual framework.
- New themes to complete the conceptual framework.

3.2.1 Literature review

A search strategy for Medline and Cochrane was developed (see Appendix 2.1) and resulted in 214 papers for the timeframe 2018 – 2023 (see the PRISMA flow chart in Appendix 2.2). A first selection based on abstract and title resulted in twenty-two included papers and 192 excluded. The selection criteria were the following:

- Out: clinical studies, studies focussing on experiences with or satisfaction with one specific medical treatment, case studies, studies about scales or measurement methods, papers in other languages than Dutch, English and French.
- In: all countries, both quantitative and qualitative research designs.

A second selection was based on the full text of all twenty-two included papers. After careful reading of the full text eleven papers were withheld. Reasons to exclude were the paper being out of scope (e.g. chronic pelvic pain with other causes than endometriosis or focus on patient-centredness of care, rather than on endometriosis) or problems with the study design (e.g. small sample size in quantitative research).

Six additional papers have been included that did not result from the search, but were found by snowballing (e.g. cited in an included paper, pop-up of journal suggesting papers that might be of interest) or upon suggestion from colleague researchers. This brought the total of included papers to seventeen. The list of included articles is provided in Appendix 2.3.

3.2.2 The development of a conceptual framework

The included papers have been read with the intention to identify factors that determine women's experiences with endometriosis, as well as the consequences of endometriosis for patients' life. These factors were first listed, then clustered in themes and subthemes and subsequently brought in relation to one another in a conceptual framework.

3.2.3 The analysis of women's testimonials

In 2023, the Belgian patients' association Behind Endo (Stories) vzw asked – beyond the context of this study – 31 women with endometriosis to write down their experiences with endometriosis to publish on their website to raise social awareness about endometriosis. These testimonials in Dutch were completed by testimonies from the French speaking part of Belgium, by contacting two patient associations in the Walloon region: Toi Mon Endo a.s.b.l and Endo Belgique. Toi Mon Endo a.s.b.l sent us 78 anonymous testimonies collected from their social media channels from inception to 9 Augustus 2023.



We analysed both the testimonials in Dutch and French by means of a thematic analysis methodology, meaning that we identified text fragments matching the themes appearing in the conceptual framework.¹²⁹ Each matching text fragment was labelled with the corresponding theme with Nvivo 1.7 coding software. Themes emerging from the testimonials which could not be matched with a concept from the framework, were given a new label, hence completing the initial framework.

Regarding the sample of testimonies, we should be cautious about the group of women represented. It is certainly not a representative sample of women suffering from endometriosis. The sample is the result of self-selection in response to patients' associations' call to witness about the difficulties endometriosis brings about in order to raise awareness. This methodology probably reduced the variability of the sample, as can be expected that women with little symptoms or positive experiences with endometriosis care did not feel called to write down their experiences. When reading through the testimonials it was clear that women with severe symptoms are overrepresented, as well as women with negative medical encounters. As we are interested in how endometriosis care can be improved, we want to learn from what goes wrong, so we are most interested in the most difficult trajectories. Yet, the underrepresentation of women with mild symptoms and positive experiences can be considered a limitation of the study.

3.3 Findings

From the selected papers we drew a list of 101 themes that were either determinants of patients' experiences with endometriosis or consequences of endometriosis for patients' life.

These themes were clustered in the following four clusters:

1. Patients' medical trajectory
2. Biographical disruption in multiple life domains
3. Quality of life
4. Potential support resources.

To the 101 themes of the original literature-based conceptual framework, 66 new themes were added, further detailing the four clusters of the conceptual

framework. The conceptual framework applied equally well for the testimonials in Dutch as in French. More than half of the new themes (n=41) were situated in the cluster 'Medical experience', which should not be surprising because the testimonials contained rich information on how women experienced the Belgian healthcare system. This information is an important complement to the conceptual framework based on the international literature, as it refers to the specificities of the Belgian healthcare context.

In what follows we will describe the recurring patterns presented in the literature as well as in women's testimonials, hence in the extended conceptual framework.

3.3.1 Patients' medical trajectory

Women suffering from endometriosis experience multiple difficulties in their encounter with medical care providers. We structured these difficulties according to the subsequent steps in a generic care trajectory: symptom onset, first presentation to a care provider, referral(s), diagnosis and treatment.

3.3.1.1 Symptom onset

Most women with endometriosis report the onset of symptoms during adolescence.¹³⁰ Women typically reported heavy bleeding and pain during menstruation (accompanied or not by headaches, fatigue, nausea etc.), but they believed it was a normal part of the menstruation process. The normalisation of the symptoms was often (initially) confirmed by significant others such as peers, siblings and/or their mother. Only in retrospect women re-interpreted their early suffering as the first symptoms of endometriosis. This observation implies that adolescents as a target group need specific attention since despite their suffering it takes a long time until they contact a care provider for help. In the next paragraph, we explain why.

3.3.1.2 First presentation to a care provider

From the literature and women's testimonials we identified several barriers to initial care-seeking.¹³¹ **Normalisation of symptoms** by women and the significant others around them was the most prominent. In addition, other



mechanisms are at work, such as **minimising symptoms** or their impact, the **acceptance of pain and discomfort** as part of being a woman, **downward social comparison** to reference persons (e.g. mothers or sisters) whose discomfort is estimated to be even worse, feelings of **shame** and the perception of **taboo, self-silencing** (i.e. silencing ones' own thoughts or feelings) and **ignorance** about normal menstruation.

'In mijn hoofd zei ik vaak tegen mezelf 'doe niet flauw, doe gewoon door', terwijl ik nu inzie dat het niet normaal was om met zo'n pijn te proberen functioneren'.

'Mon parcours est bien compliqué. Il a commencé dès ma première année de règles. J'ai été réglée assez tôt (10 ans) et c'était extrêmement abondant et douloureux. Lors de la première visite, on m'a expliqué que c'était normal d'avoir mal, que je ne devais pas m'inquiéter, que le ressenti de ces fortes douleurs étaient aussi lié à mon très jeune âge. Les années sont passées et rien ne s'est amélioré.'

These mechanisms contribute to a **women-related diagnostic delay**, i.e. the delay occurring between the onset of symptoms and the recognition by the woman that she can no longer self-manage but instead requires medical attention.

Factors facilitating initial care-seeking on the contrary were **being informed about endometriosis** and **the encouragement of significant others to make an appointment**.

Once women decide to seek help, new hurdles come their way. The most important one is the **inadequate knowledge and expertise** of the care provider they contact, which translates into several adverse reactions. The most frequently reported unhelpful reaction was **misdiagnosis** (such as appendicitis, irritable bowel syndrome, influenza, fibromyalgia, chronic fatigue syndrome, or depression), followed by **being laughed at, not being taken seriously, normalization or minimalization of symptoms, blaming the victim** (e.g. bad eating habits or wearing the wrong underwear) and **psychologizing** (e.g. 'it's all in your head'). In addition, women

experienced being provided with **wrong information** or inappropriate advice. **Gynaecological violence** has also been reported.

'Voilà, oorzaak gevonden, je bent een griepje aan het krijgen! Serious, Doc!?! Dit is écht wel erger dan een buikgriepje, hoor! En mijn pijn lag veel lager dan waar zij keek met haar echo, maar daar had ze geen oren naar'.

'Ik herinner me wel dat ik eens tegen mijn huisarts gezegd heb dat ik veel last had van mijn darmen tijdens mijn regels, maar dat werd naar mijn gevoel afgewimpeld onder het motto 'veel vrouwen hebben daar last van'.'

'Cela fait des années que je crie avoir de l'endométriose digestive mais aucun médecin ne cherche à cet endroit. Tous se sont concentrés sur l'utérus où j'ai seulement quelques atteintes. Cependant, depuis peu, je me mets à saigner au niveau du rectum pendant les règles, ce qui indique donc une atteinte au niveau du colon, et pourtant aucun spécialiste ne m'écoute.'

'J'ai eu mes premières règles à 11/12 ans. Elles ont toujours été extrêmement douloureuses (aucun antalgique ne les soulage), très abondantes et très longues (7/10j). J'ai vu ma première gynéco environ 6/8 mois plus tard, un amour. Mais après essai de pilule, homéopathie, multiples médicaments; recherche par échographie, IRM, elle s'est retrouvée à me dire que je n'aurai plus mal quand j'aurai des enfants. Cela m'a atterrée, beaucoup atteinte, j'étais jeune, collégienne, seule avec ma douleur. J'ai continué au fil du temps à taper à d'autres portes, mais j'étais de moins en moins motivée, de toute façon on ne trouvait pas.'

'Cette gynécologue m'a enfoncé le speculum d'une violence (parce que sa stagiaire n'y arrivait pas...) telle que j'ai failli tomber en syncope. J'ai dit stop mais ça n'a rien changé... ensuite elle m'a enfoncé l'écho et quand elle l'a retiré, c'était plein de sang.'

Other consequences of care providers' lack of knowledge are **patients' own**



search for information and **patients being referred** because the care provider recognizes his/her limitations.

Inadequate knowledge and expertise contribute to a **clinician-related diagnostic delay** which is situated between the first presentation to a care provider and diagnosis.

The **diagnostic delay** is perceived by women as wasted time which leads to worsening symptoms and increasing harms to the body. Patients attribute it to a lack of knowledge and expertise among healthcare providers, both in primary and secondary care in combination with the negative results of imaging. They continue self-management practices (e.g. resting, switching diets, pain medication), switch to other care providers, and keep searching for (online) information themselves.

'Is het juist dat we zo hard moeten vechten voor de juiste zorg, gemiddeld zo lang moeten wachten (8 jaar) op een diagnose? In die tijd heeft de endo al heel veel kunnen groeien, organen kunnen vernietigen, je hele leven van je afnemen. Nee, dat is niet juist.'

3.3.1.3 Diagnosis

Diagnosis is often not a binary state (present or absent), but a 'messy process' covering a difficult trajectory from symptoms to suspicion of endometriosis, to imaging, to confirmation by means of ultrasound, MRI or laparoscopy. In addition, often the extent of the endometriosis can only be fully understood during surgery, because not clearly visible through imaging. Once the diagnosis is known women get validation of their symptoms. The diagnosis also brings about feelings of relief. Although relief is the most commonly described feeling, the shock of having an incurable chronic disease is also reported, which turns the diagnosis into an ambivalent experience. The diagnosis leads to empowerment and regaining of control of their lives. It finally confirms that women did not imagine the symptoms, that they are not crazy, that there is a real bodily problem with a name. For a group of patients, the diagnosis confirmed what they already figured out for themselves (self-diagnosis) or at least suspected, others however heard of endometriosis for the first time. The diagnosis of endometriosis gave them the legitimacy to enter the world of endometriosis patients and take the patient role.

'Voor het eerst werd bevestigd dat het niet 'tussen mijn oren' zat en kreeg ik zelfs beeldmateriaal te zien van mijn letsels. Ik kon de ziekte in de ogen kijken. Hoewel enerzijds een opluchting, toch viel het afscheid van mijn gezonde lichaam me zwaar.'

'Suite aux différents examens il en a été conclu que j'étais atteinte de SOPK (syndrome des ovaires polykystiques) mais aussi d'endométriose. J'ai ressenti un soulagement au moment du diagnostic, JE N'ÉTAIS PAS FOLLE!!'

Diagnosis is also intertwined with fertility problems and treatment. Both in the literature and in the patient testimonials we found the observation that the diagnosis of endometriosis is 'facilitated' by fertility issues.¹³² In other words, the search for explaining fertility problems may lead to the diagnosis of endometriosis, more than reported symptoms do, as if fertility problems circumvent the subjectivity that is associated with the (other) reported symptoms, hence cannot be that easily dismissed.

'Na ons eerste miskraam kon de gynaecoloog 'gelukkig' vertellen waarom ik al die jaren zo'n pijn had. Endometriose... Ik had eindelijk een 'sticker'. Waar ik niet rouwig om was want mijn pijn werd eindelijk 'herkend'.'

Some patients described that once a physician suspected endometriosis based on the reported symptoms the scheduling of diagnostic tests and ultimately a laparoscopy followed rapidly to confirm the suspicion, others reported waiting times up to several months. Waiting times for consultations as well as for surgery also contributed to patients' distress.

'Op 14/11/2022 stond de eerste afspraak gepland waarbij hij aan de hand van medische beeldvorming en bepaalde plekken intern "voelen" vermoedde dat er inderdaad sprake was van endometriose. Maar zonder een kijkoperatie kan dit echter nooit vastgesteld worden en blijft het bij een vermoeden. Dr. [Naam arts] raadde dan ook aan om zo snel mogelijk een laparoscopie in te plannen en zo stond ik 2 weken later al op de planning.'



'En me documentant un peu sur les symptômes, j'ai directement trouvé ce que j'avais. J'en ai donc parlé à mon médecin traitant et à ma gynécologue qui m'ont directement pris au sérieux et m'ont envoyée à [Nom de ville] faire des examens plus spécifiques et pour consulter chez un gynécologue spécialisé. En même pas 30 minutes, j'ai été diagnostiquée d'endométriose, d'adénomyose.'

'In februari 2016 ben ik dan effectief voor de eerste keer geopereerd. De gynaecoloog heeft de operatie echter moeten stopzetten aangezien de endometriose ook aan/in organen zat en daar een gespecialiseerde techniek voor nodig was die ze enkel in [Naam stad] konden uitvoeren. Ik heb uiteindelijk negen maanden moeten wachten op mijn eerste consultatie in [Naam stad] en nog eens een jaar voor mijn tweede operatie.'

3.3.1.4 Treatment

After trying several treatments and/or ultimately undergoing surgery, a reduction of symptoms is expected and usually also experienced. However, for some patients it was disappointing in the sense that symptoms were not (completely) gone, or that the endometriosis caused damage to the body leading to a lowered quality of life even after treatment.

'Op papier blijf ik inderdaad gespaard van endometriose sinds mijn eerste grote ingreep drie jaar geleden (alsof je ooit van deze chronische ziekte kan genezen, not!). In werkelijkheid vecht ik elke dag met de gevolgen die de ziekte in mijn lijf achterliet. Een aspect van endometriose dat nog zwaarder onderbelicht wordt dan de ziekte zelf. De endometriose is nu misschien weg maar mijn levenskwaliteit is sterk verminderd.'

'Tot de dag van vandaag kan ik na de operatie van maart 2022 nog steeds niet voltijds aan het werk. De pijn en vermoeidheid blijven groot. Ik heb mijn levensritme moeten aanpassen, en dat blijf ik moeilijk vinden. Er is ook een traject opgestart bij de pijnkliniek.'

'Après ça, ce fut un rendez-vous dans un centre d'endométriose, ou les rendez-vous se sont enchaînés avec kiné, nutritionniste,

médecin de la douleur etc. On m'a prescrit plusieurs traitements qui n'ont pas spécialement fonctionné, du moins au début et à la fin plus rien. Je suis sous pilule en continu, je suis actuellement en traitement Cymbalta, Célébrex, Laroxyl, Izalgi, J'ai récemment été hospitalisée pour la kétamine, mais je suis toujours au point mort car malgré tout ça les douleurs sont toujours là, je suis un peu perdue dans ma vie car j'ai l'impression d'être perdue.'

Furthermore, recovery from surgery can be a long and challenging process, which is often underestimated. In the literature post-operative support was emphasized as an important patient need.¹³³

'In de komende dagen en weken werd duidelijk hoe lang de revalidatie periode zou duren. Een moment zal mij altijd blijven. We waren ongeveer 10 dagen na de operatie. Yannick kwam even kijken of ik nog niet in de wc gezakt was. Ik spendeerde hier veel van mijn tijd. Ik had enorm veel last van bloederige urine door de stents die ze geplaatst hadden in de verbindingen tussen mijn nieren en blaas zodat deze niet zouden dichtgroeien. De tranen rolden over mijn wangen. "Ik wil hier niet meer zijn.'

'Je trouve que l'on devrait, après une opération ou même après ton diagnostic, parler et mettre en place une prise en charge pluridisciplinaire. Je me suis sentie fort seule après mon opération et j'avais encore beaucoup de douleurs. Je ne savais pas vers qui me tourner.'

In addition, relapse of symptoms after a certain time were reported, together with feelings of despair and grief. Especially when the symptoms were (again) not taken seriously, because it was in some way expected that



surgery would have solved the problemⁱⁱ. If symptoms remained or came back after surgery, some patients encountered misunderstanding or disbelief on the part of the care provider. Some patients reported that they felt experts gave up on them.

‘Ondanks het feit dat de diagnose snel werd gesteld (waar ik tot de dag van vandaag nog heel gelukkig om ben) was er na de 1ste operatie veel onbegrip van artsen. Ze zeiden me dat de pijn in mijn hoofd zat en dat ik dan maar eens naar mijn darmen moest laten kijken.’

‘En toen ik na al die ingrepen wel bij een endometriose-arts terecht kon, met al mijn vragen over mijn lichaam en mijn toekomst, was die heel duidelijk. ‘In zo een buik komen wij niet meer.’ Tot zover dus de ondersteuning aan langdurige patiënten... Je chirurgische geschiedenis wordt als te complex beschouwd en je wordt volledig met de rug tegen de muur gezet. Het geeft mij in alle eerlijkheid weinig goede moed om de komende jaren te trotseren.’

‘Récemment le gynécologue m’a dit qu’il ne pouvait plus rien pour moi, c’était le 21ème gynécologue que je voyais.’

Finally, side effects (e.g. hair loss, headaches, anxiety, panic attacks, mood swings, depression, weight gain) of (post-surgical) hormone treatments (of which some cause a menopausal state) were underestimated.

‘Door de zware hormonen had ik dagelijks hoofdpijn en heel vaak aanvallen van migraine. Daarbij kwam nog dat die hormonen zorgden voor heel wat extra kilo’s en aangezien ik een slank iemand was, mocht ik daar toch niet over klagen zeker. Het was ook jaren effectief het minste van mijn zorgen, maar de hormonen maakten dat ik gevangen zat in een ander lichaam, zowel fysiek als mentaal. [...] Ik heb dat meerdere malen proberen duidelijk te maken aan

mijn prof in [stad], aan gynaecologen, ... maar niemand had effectief begrip voor alle bijwerkingen die ik had.’

‘Deuxièmement, je trouve que le fait de prescrire un moyen de contraception n’est pas la solution, pour moi la contraception a des effets secondaires que beaucoup de médecins nient. Ce qui n’est pas normal.’

3.3.1.5 Patient needs in relation to their care trajectory

With their medical experience in mind, women affected by endometriosis formulated several needs, which were also mentioned in the international literature.^{134, 135}

Firstly, there is a need for more expertise and accurate knowledge about endometriosis at all levels of care, but this was especially pertinent in primary care. Also, awareness among the population at large, and adolescents in particular should be strengthened. By extension, painful menstruation should not be considered as normal and part of being a woman.

‘Mijn endometrioseverhaal werd dus duidelijk vertroebeld door verkeerde opvattingen rond menstruatie, wat uiteindelijk heel wat onnodig leed veroorzaakte. Ik hoop dan ook uit de grond van m’n hart dat dit soort bewustmakingscampagnes dit snel verandert.’

‘De huisarts waar je als eerste aanklopt, is helaas niet goed geschoold op dit gebied en stuurt jonge meisjes weg met anticonceptie en “menstruatiepijn hoort er nou eenmaal bij”. Deze eerstelijnszorg moet alert zijn op de symptomen, zodat jonge meiden serieus worden genomen. Ik hoop met heel mijn hart dat meiden/vrouwen in de toekomst een minder lange weg hoeven af te leggen.’

ⁱⁱ To date it is well known that endometriosis is a chronic inflammatory disease which needs hormonal treatment, also after surgery.



'Plus de visibilité sur la maladie. Plus d'information de la part des spécialistes.'

Secondly, the dominant theme in women's testimonials was the need to be heard with empathy and respect. The medical experiences of women suffering from endometriosis were permeated with their symptoms not being taken seriously, minimized, normalized, psychologized or even laughed away.

'Ik trof daar een lieve arts die éindelijk echt naar mij luisterde en mijn klachten écht serieus nam. Ik voelde een enorme opluchting, hier hoefde ik niet te strijden om gehoord te worden.'

'Errance médicale pendant 18 ans, je souhaiterais que les gynécologues 'généraux' puissent écouter, identifier la maladie et nous diriger automatiquement vers un spécialiste de la maladie. Qu'ils arrêtent de banaliser les douleurs.'

Thirdly, coordination of care by multidisciplinary endometriosis teams was suggested to relieve the pressure for patients to organize this care themselves and enhance the quality of care.

'Deze onwetendheid deed zich ook voor onder hulpverleners en voedde mijn onzekerheid. Het gebrek aan een allesomvattend endometriosesteam, bestaande uit artsen, verpleegkundigen, kinesisten, diëtisten en psychotherapeuten, zorgde voor een grote druk om steeds zelf op zoek te gaan naar mogelijke hulp. Je eigen zorg coördineren is geen voor de hand liggende taak om zonder ruggensteun uit te voeren.'

'Je trouve que l'on devrait, après une opération ou même après ton diagnostic, parler et mettre en place une prise en charge pluridisciplinaire. Je me suis sentie fort seule après mon opération et j'avais encore beaucoup de douleurs. Je ne savais pas vers qui me tourner.'

Fourthly, the development of a care plan (including pre-operative and fertility counselling, post-operative support and follow-up) would be helpful for

patients to be correctly informed about all treatment options, their effectiveness and potential harms, to be encouraged to make an informed choice, and to build realistic expectations about the future.

'J'ai aussi eu l'impression que je n'avais pas beaucoup d'options comme traitement. On m'a directement proposer la chirurgie, pas d'autres alternatives. J'ai eu peu d'explications sur le risque de la chirurgie et le après.'

Finally, patients proposed a special type of sick leave specifically for endometriosis patients and the reimbursement of hormonal treatment.

'Avoir droit à des congés maladies spéciaux pour l'endométriose serait aussi un plus car encombrer une salle d'attente de généraliste pour demander un certificat car on est en crise est juste absurde quand on sait que les généralistes sont surchargés.'

'Il s'agit d'une maladie terriblement invalidante pour laquelle des choses devraient être mises en place : le remboursement des traitements (mon traitement hormonal n'est pas considéré comme un contraceptif donc pas remboursé et est extrêmement coûteux), des jours de congé vis à vis du travail pour les jours de crise... '

3.3.2 Biographical disruption of all life domains

Although many treated or asymptomatic patients experience minimal impact on their everyday life, endometriosis can cause a biographical disruption in all life domains. Biographical disruption means the disruption of "the structures of everyday life and the forms of knowledge which underpin them."¹³⁶ The disruption requires women to change their behaviour and identity in order to accommodate the effects of the disruption on their lives and relationships.

3.3.2.1 Causes of biographical disruption

The causes of the biographical disruption experienced by endometriosis patients are threefold:

1. Disabling and unpredictable symptoms



First of all, the disabling and unpredictable nature of the symptoms dominate patients' lives. Appointments need rescheduling, social activities are cancelled, classes are missed, learning deficits are built, prejudices of friends, colleagues, acquaintances are shaped, job capacity and working hours are reduced, and intimate life is destroyed.

'Jaren heb ik afgezien en hoe ouder ik werd, hoe slechter en onleefbaarder het werd. Mijn moeder en toenmalige vriend hadden gelukkig veel begrip en zorgden goed voor me. Heel veel afspraakjes moest ik door de pijn afzeggen. Weekendwerk afzeggen, want op het laatst had ik zoveel last dat ik amper 10 dagen pijnvrij was. Eigenlijk was het meer uitblazen om de volgende menstruatie aan te kunnen.'

'Je voulais aussi parler de l'aspect social dans les rapports avec son conjoint. Vivre avec l'endométriose dans une vie de couple n'est pas toujours facile. Tout d'abord dans les relations sexuelles. Les rapports douloureux, la fatigue, la pilule en continu qui diminue parfois la libido,... Pas facile d'expliquer tout ça à son compagnon et surtout de se faire comprendre. Plusieurs fois avec mon compagnon nous avons failli nous séparer à cause de ça. [...] La fatigue chronique pas évidente tous les jours, que ce soit dans vie privée que professionnelle.'

2. Time and energy spent searching for a diagnosis and subsequent treatment

On top of the impact of symptoms, patients need to structure their lives in function of the time they spend on searching for a diagnosis and subsequent treatment. This search is particularly troublesome, is spread out over several years, and causes a lot of distress. The question 'what is wrong with me' constantly remains at the back of patients' mind. Patients searched for information online, consulted physicians and other care providers and still many of them coincidentally bumped on the information that led them to suspect endometriosis (e.g. in a newspaper article). The search for a diagnosis and subsequent treatment could be facilitated, hence shortened by knowledgeable

generalists and gynecologists, care providers to whom women tend to present first.

'Op mijn 23ste legde ik mijn klachten voor aan een prof. gynaecoloog van UZ [stad], en informeerde ik zelf of ik niet mogelijk endometriose kon hebben. Ik had mijn symptomen opgezocht, en vond dat deze erg leken op de symptomen die beschreven worden bij endometriose. Ik herinner me nog goed dat, hoewel ik over het algemeen assertief en kritisch ben, ik hier toch veel moed voor moest verzamelen. Ik had het gevoel dat ik op het consult als 'overbezorgd', of een hypochonder zou overkomen, die 'teveel had opgezocht op google.'

'Ik begon tijdens dat consult weer over endometriose en zei dat de pijn zich ook laat voelen bij het plassen. Wéér werd ik niet gehoord en kreeg ik als antwoord 'ik kan je niet helpen'. Er werd zelfs geen onderzoek of doorverwijzing naar een andere arts voorgesteld! In tranen verliet ik de praktijk. Een second opinion bij een andere gynaecoloog in hetzelfde ziekenhuis liet me al even troosteloos achter; wat moest ik nu doen? Die pijn kwam toch van ergens?'

3. Disbelief and dismissal of symptoms

The symptoms and the search for a diagnosis are made even heavier to carry when confronted with disbelief and dismissal of symptoms by care providers, but also significant others (e.g. partners, siblings, parents, teachers), confidants. In the face of normalization, minimalization and psychologization of symptoms, its particularly difficult not to start doubting oneself. In the literature and in women's testimonials, young age was linked to an increased risk of not being taken seriously.¹³⁷ Especially adolescents are not believed and silenced with normalizing statements (e.g. it is part of being a woman) or a contraceptive pill and painkillers at best.

'Ja, eerlijk gezegd, voel ik mij vaak eenzaam, en ja, ik ben soms heel boos op de wereld en vooral op mijn eigen lijf, het vertrouwen in mijn lijf ben ik kwijt geraakt. Ik voel mij ook vaak beoordeeld in negatieve zin, omdat je hoort dat er dingen achter je rug om over je



worden gezegd. Al zoveel heb ik voorbij horen komen, 'ze is gewoon te lui om te werken', 'och, die heeft ook altijd wat', 'wat moet je eigenlijk met háár?', 'oh, kun je niet weg, kan ze dat niet alleen?', 'ze is toch geopereerd, is ze nu nóg niet beter?', 'waarom deelt ze plaatjes over endometriose? Voor aandacht?' Zomaar een greep uit de voor mij kwetsende opmerkingen van mensen om ons heen. Het mentale stuk is voor mijn gevoel onlosmakelijk verbonden met deze ziekte. Buitenom de artsen die je zowat moet overtuigen dat je pijn echt is. Zo krijg je dit nog dubbel op door mensen in je omgeving.'

3.3.2.2 Consequences of biographical disruption

The consequences of the biographical disruption caused by endometriosis are pervasive and numerous. Women do not only start to **distrust care providers** and develop all kinds of **self-management strategies**, their life is also put on hold, opportunities in life are missed, quality of life is severely reduced. The latter is part of the next sub chapter.

Women's distrust in care providers triggers decisions about their care trajectory. They change doctors or clinics in search for someone to understand their symptoms and come with a diagnosis, they start a (long) search for adequate care and treatment even outside the country borders.

'Mijn pijn kwam terug en mijn buikgevoel werd sterker en sterker dat mijn buik helemaal niet proper was maar dat er nog veel te veel endometrioseweefsel aanwezig is. Ik merkte door kleine dingen ook dat ik hierin niet serieus werd genomen en het vertrouwen in het ziekenhuis ebde langzaam weg. Ik liet me ondertussen op een wachtlijst zeten voor een second opinie in een ander ziekenhuis.'

'Ik bezocht de ene dokter na de andere, sinds mijn dertien jaar. Vanaf mijn 14 jaar nam ik de pil want er werd geen oorzaak gevonden en dit was de 'oplossing'. Het hielp, maar niet voor altijd. Elke pil uit het gamma van de apotheker heb ik geprobeerd, soms zelfs twee tegelijk.'

'Dans mon malheur d'être atteinte d'endométriose, j'ai eu la chance d'avoir un diagnostic plutôt rapide, par la force, la persévérance et la

conviction que cette maladie me dévorait de l'intérieur. J'ai vu plusieurs gynécologues / spécialistes jusqu'à ce que l'une me prenne au sérieux et me traite correctement.'

3.3.3 Quality of life

It is clear from the international literature and women's testimonials that **endometriosis impacts all life domains**, not only because of the destructive symptoms, but also because of the search for information, understanding, diagnosis and treatment, which takes a lot of effort.¹³³ Hence women's quality of life is severely reduced. We zoomed into five life domains: mental health, identity, sexual life, job and education, and social life.

3.3.3.1 Mental health

The impact of endometriosis on women's mental health can be particularly severe. Women reported a range of symptoms: depression, burn-out or exhaustion, anxiety, suicide thoughts, feelings of despair, anger, guilt, sadness, the reduction of enjoyment of life and worries about e.g. infertility and passing endometriosis on to the next generation.

'In de afgelopen maanden dat ik zó ziek was, heb ik meerdere malen contact gehad met mijn artsen. Wanhopig heb ik gezocht naar hulp en verlichting voor mijn pijn. De hulpverleners wezen op den duur allemaal naar elkaar. Zo blijf je ronddwalen zonder échte hulp en dit drijft je echt tot wanhoop. In al die jaren heb ik nooit aan mijzelf getwijfeld, ook al werd ik in bepaalde 'hokjes' weggezet. Deze periode begon ik wel aan mijzelf te twijfelen, ook al wist ik diep van binnen dat mijn pijn niet 'tussen mijn oren' zat. Ik was gewoonweg te moe om te blijven strijden om gehoord te worden.'

'Aujourd'hui ma plus grande crainte est que ma fille qui va avoir 12 ans (pas encore réglée) développe aussi l'endo mais je reste positive car ce n'est pas systématique.'



3.3.3.2 Identity and self-image

Endometriosis impacts women's identity and self-image as they may encounter a loss of self-confidence, they may feel less feminine or different from other women, and they may perceive themselves as weak. Endometriosis also changes their embodied self as they experience the loss of a healthy body, alienation from their own body (e.g. because their looks changed by gaining weight), loss of control over their body, they feel abandoned by their body, and perceive their body as broken. The body is perceived as a problem when in pain and discomfort, and more specifically when pregnancy was not forthcoming.

'De hormonen maakten dat ik gevangen zat in een ander lichaam, zowel fysiek als mentaal. Ik was een ander persoon in het lichaam van iemand anders.'

'De positieve mindset is soms ver te zoeken helaas, mede door de frustratie dat mijn lijf me in de steek laat.'

3.3.3.3 Sexual life

In the literature sexual dysfunction and distress are well documented, however in the testimonials it is mentioned only a few times, probably because most (Dutch speaking) women did not feel comfortable enough to address this topic in a (non-anonymised) written testimonial which they agreed to be published on a patients' association website.^{133, 138-141} The same probably accounts for troublesome relationships and break-ups caused by the illness. In the testimonials we analysed, women mostly praised their partners for their support, patience, understanding, and care.

'Ook op seksueel gebied kom je als koppel in heel ander vaarwater terecht. Alvorens ik de diagnose kreeg en dus mijn pijnen nog had, was intimiteit op seksueel vlak erg nihil; ik had al pijn in mijn buik, dus wat zou penetratie of een orgasme me opleveren? Als je na seksueel contact nog 2 dagen zeurende buikpijn hebt, dan leer je wel om seksuele intimiteit te parkeren. Toen nadien de Decapeptyl insputingen gestart werden en de menopauze zich aanmeldde, kwam ik in een ijtijd terecht en had ik helemaal geen zin in seks! Dit was voor ons als koppel nieuw, en vroeg vooral van mijn man veel

begrip en geduld, wat hij gelukkig ook heeft. Maar dat wil niet zeggen dat het gemakkelijk is, ook niet als 'partner van...'. Na de operatie was het dan weer een verbod op seks, omdat mijn onderbuik zich moet herstellen. En zo blijven we bezig. Zoekend als koppel naar wat werkt om ons steeds 'een koppel' te blijven voelen, na het wegvallen van datgene wat een liefdesrelatie onderscheidt van een vriendschapsrelatie.'

'Dans l'intervalle, j'ai eu un copain et les rapports étaient très douloureux... je pensais avoir un problème et je n'étais pas avec un partenaire qui faisait spécialement attention à comment m'aider pour que ça soit plus un plaisir qu'un moment désagréable donc forcément, ça n'a pas aidé... Depuis 2018, je suis célibataire... ça m'est resté...'

3.3.3.4 Job and education

As endometriosis can manifest itself at an early age, young girls are confronted with all kinds of problems at school: not being able to participate in sport lessons, being absent, needing flexible deadlines for assignments and exams, fear of leakages because of the heavy bleeding, unsupportive reactions of peers and teachers, and quitting studies.

'Uiteindelijk werd ik op mijn 13de aan de pil gezet, omdat ik steeds school miste vanwege de pijn voor en tijdens mijn menstruatie. Dit hielp een beetje, het ouder worden ook iets. Ik moest me volproppen met pijnstillers om naar school te kunnen of te kunnen werken en feestjes moest ik afzeggen als ik ongesteld was.'

'Je suis étudiante en Master 2 et j'ai dû arrêter à cause de mes douleurs qui sont invalidantes et m'empêchent de poursuivre mes études et donc de travailler. Je me retrouve dans une situation où je suis obligée d'être financée par ma mère pour toutes les choses de la vie. J'ai arrêté mes études à contre cœur vraiment car j'aimais étudier mais la maladie m'empêche, cela faisait 2 ans que j'essayais de finir le Master 2 et je l'avais même allégé.'



In later life, job opportunities are reduced because needing to work part-time, a large number of sick days, and reduced productivity, with unsupportive reactions of colleagues and employers on top. Some women even report job loss because of endometriosis.

'Totdat ik instortte, het was ineens voorbij. Langdurig ziek thuis. Re-integratiepogingen lukken nu niet. Mijn contract loopt nog tot september en dan heb ik geen baan meer.'

'Als het werk hier thuis en het werk voor school gedaan was, dan was het ook over & out met mij. Dan kon ik enkel nog op de zetel rusten, want dan was mijn lichaam op en ik moest immers weer oké zijn tegen maandagochtend. Dit was op lange termijn niet houdbaar en daarom werk ik sinds twee jaar noodgedwongen parttime en dat geeft me eindelijk ademruimte.'

'Ne parlons pas de mon ancien employeur qui ne voulait pas que je me fasse opérer car pour lui le post-op était trop long LOL !!! Depuis j'ai démissionné et il osé encore ne pas comprendre pourquoi... il m'aura fallu 4 ans pour quitter cet employeur toxique mais j'y suis arrivée...'

3.3.3.5 Social life

Women with endometriosis report a significant reduction of their social activities. In their attempt to balance discomfort and outdoor activities, they encounter both supportive and unsupportive reactions, the latter leading to a decline of their social network. By consequence they feel misunderstood and they experience loneliness and isolation. Women also speak about needing to change their plans in function of disabling symptoms, missing out or having no social life at all.

'Ma vie sociale avec l'endométriose est pas top. Je rate beaucoup de fêtes, d'occasions de sortir en famille, de marcher, de faire du sport, de travailler !'

'Toutes ces choses ne me facilitent pas la vie pour mes relations amoureuses et amicales. Beaucoup de personnes ont encore des

difficultés à comprendre le changement qui peut s'opérer en l'espace d'une heure sur mon corps, ou que j'aie super bien à un moment et, 15min après, hyper mal.'

In addition, they are no longer able to fulfil their social roles in the way they would want to fulfil them. Especially in the partner and mother role they feel dependent on loved ones.

'Toen ik na 5 dagen ziekenhuis naar huis mocht, ontpopte mijn man zich tot mijn persoonlijke verpleger. Hij deed iedere ochtend mijn steunkousen aan, zorgde voor mijn urinezak, hielp me met douchen, installeerde me in de zetel, nam het huishouden op zich (tillen en bukken was verboden voor mij) en installeerde mij 's avonds in bed met de nodige kussens.'

'Al deze jaren kan ik niet voor mijn zoontje zorgen zoals ik echt zou willen, hij is in dit alles wel mijn drijfveer. Voor hem sta ik elke dag op, ook al is het spugend. Ik probeer zoveel mogelijk leuke dingen met hem te doen, is het niet groot, dan is het klein hier thuis, net zo waardevol. Zo klein als hij is, is hij zich al heel bewust van het feit dat mama niet alles kan en mama ziek is.'

'Par moment je ne sais même pas m'occuper de mes enfants! (Oui, grâce à Dieu j'ai deux magnifiques enfants! malgré plusieurs fausses couches.)'

3.3.4 Potential support resources

Although some women report a lack of support in their entourage, others emphasise the support they receive from significant others (e.g. mother, siblings, peers, partner) and virtual communities (via social media).

3.3.4.1 Significant others

Among the significant others, we note the special importance of the mother, both in the literature as in women's testimonials.^{141, 142} Mothers have a large impact on how their daughter copes with endometriosis. In the best case, mothers are very supportive and encourage their daughters to seek



professional help in the early phase of their medical trajectory. In the worst case, mothers downplay the symptoms and tell their daughters they just have to learn to live with the pain. An interesting observation is that best and worst cases seem to occur independent of whether mothers have suffered from endometriosis themselves. However, this observation would need confirmation of quantitative studies.

'Je souffre d'endométriose depuis +/- 10 ans maintenant et pour moi le plus dur c'est la situation avec mon entourage, au début ils sont compréhensifs, curieux de savoir à propos de cette maladie mais au fil du temps je constate que malheureusement il n'y a plus vraiment d'intérêt, on banalise, on se dit que après l'opération on n'en parle plus et cela pour moi est plus dur à supporter que la souffrance physique lié à l'endométriose.'

'Hello, alors moi pour mon parcours j'ai eu une première gynécologue qui m'a diagnostiqué la maladie mais qui m'a lâchée comme ça dans la nature et voilà débrouille toi. Heureusement pour moi (ou malheureusement) ma maman en est atteinte également depuis toute jeune et a donc pu me prendre sous son aile afin de mieux vivre ça.'

Mothers' and peers' (including siblings) observations help to distinguish between normal and abnormal menstrual pain.¹⁴¹ The literature mentions women who considered their symptoms as normal, but were sent to their general practitioner or gynaecologist by a friend or relative who incidentally captured them during a painful period and told them it was not normal.¹⁴²

'Zoals je hierboven kan lezen, had ik die onderzoeksstoel van de gynaecoloog in mijn jonge jaren vermeden. Deze afspraak werd dan ook geregeld door mijn zus omdat zij het hoognodig vond dat ik een keer ging laten onderzoeken wat er werkelijk mis was met mij.'

3.3.4.2 Patients' associations and social media

Social media such as Facebook are mentioned as ways to meet women with similar experiences and who become an important source of support and understanding. In addition, patients' associations and virtual communities provide women with information about symptoms, diagnosis and treatment, but also physicians who may be more supportive, and clinics with high rated expertise. Finally, contacts with online groups and patients' associations give women a sense of belonging to a community.

'Via facebook ben ik terecht gekomen in de besloten groep [...]. Dit is een hele fijne groep, het heeft me veel geleerd en goede contacten met lotgenoten opgeleverd. Ik heb het gevoel dat je in die groep alles bespreekbaar kunt maken en er altijd iemand luistert en je begrijpt.'

'Pendant le confinement, les douleurs se sont intensifiées, encore. Désespérée, j'ai lancé un appel à l'aide sur les réseaux sociaux. J'ai obtenu plein de témoignages et on m'a parlé pour la première fois de l'endométriose (j'avais 21 ans). J'étais contente d'avoir enfin des pistes et beaucoup m'ont recommandé le CLE^{jj}.'

^{jj} Centre Liégeois d'Endométriose.



3.4 Feedback from patients' associations

In qualitative research member checks or respondent validation is commonly used to improve the credibility of the findings. Findings are returned to the participants to check for accuracy. However, since we analysed testimonies of patients collected through patient associations, we didn't ask the individual women for their feedback, but the Belgian patients' associations. Stakeholder reviews of draft findings is described as a good research practice.¹⁴³

Apart from a few minor additions, two comments were remarkable because they were shared by the patients' associations and not identified in the individual women's testimonials during our analysis. First, the representatives of the patients' associations expressed their concern about the surgical expertise among gynaecologists and surgeons in Belgium. According to the associations, this results in serious adverse consequences for some patients, e.g. complications, repeated surgery, additional harm to the body and persistent pain. Second, as a consequence of this proclaimed inadequate surgical expertise, women experience the necessity of seeking treatment abroad, which has extensive practical and financial implications.

Because this feedback was received after the two face-to-face meetings with the clinical experts, we were not able to confront the clinical experts with this feedback.

However, the feedback from the patients' representatives cannot be detached from the current lack of cure for endometriosis, and the fact that contemporary medical and surgical treatments for endometriosis are not only ineffective for an important proportion of patients, but also may carry serious harms for some. The feedback underlines the importance of the provision of comprehensive and accurate information to the patients (and their significant others) before the start of any treatment. The limitations of the current therapies and the potential side-effects should also be discussed. In addition, the feedback underlines the need for quality assessment based on objectively measured quality indicators, so that gaps in expertise and experience can be identified and quality improvement cycles can be started. Lastly, as stated above, individuals with more severe symptoms and/or negative medical encounters may be more eager to voice

their experiences and grievance than those who were released from (most) complaints and pain.

Key points:

- **Women suffering from endometriosis experience multiple difficulties in their encounters with medical care providers;**
 - Initial care-seeking is delayed because of for example normalisation or minimisation of symptoms, acceptance of pain and discomfort as part of being a woman, feelings of shame, and ignorance about normal menstruation;
 - Women report inadequate knowledge and expertise of the (primary) care provider they contact, resulting in misdiagnosis, not being taken seriously, normalisation or minimisation of symptoms, blaming the victim, and psychologizing, in addition to being provided with wrong information or inappropriate advice;
- **Women formulated several needs:**
 - The need for more expertise and accurate knowledge about endometriosis at all levels of care, which was especially pertinent in primary care. Also, awareness among the population at large, and adolescents in particular should be strengthened;
 - The need to be heard with empathy and respect;
 - Coordination of care by multidisciplinary endometriosis teams was suggested to relieve the pressure for patients to organize this care themselves and enhance the quality of care;
 - The development of a care plan (including post-operative support and follow-up) would be helpful for patients to be correctly informed about all treatment options, their effectiveness and potential harms, to be encouraged to



make an informed choice, and to build realistic expectations about the future;

- Although many treated or asymptomatic patients experience minimal impact on their everyday life, endometriosis can cause a disruption in all life domains with consequences for their mental health, identity and self-image, sexual, social and professional life;
 - The disabling and unpredictable nature of the symptoms dominate patients' lives;
 - On top of the impact of symptoms, some patients need to structure their lives in function of the time they spend on searching for a diagnosis;
 - The symptoms and the search for a diagnosis are made even heavier to carry when confronted with disbelief and dismissal of symptoms by care providers, but also significant others (e.g. partners, siblings, parents, teachers);
- Although some women report a lack of support in their entourage, others emphasise the support they receive from significant others (e.g. mother, siblings, peers, partner) and virtual communities (via social media). Especially mothers have a large impact on how their daughter copes with endometriosis. Social media are ways to meet women with similar experiences and who become an important source of information, support and understanding;
- Patients' associations consider the surgical expertise in Belgium as inadequate, therefore they seek treatment abroad.

4 ENDOMETRIOSIS CARE IN BELGIUM

This chapter is composed of two main sections. In the first section, we provide results of the analysis of hospital data (i.e. Technical Cell (TCT) data, see Box 5), in which we focus on hospital admissions with endometriosis as the principal or secondary diagnosis in 2016-2020. In the second section, the results are described of the survey that was distributed to all Belgian hospitals and in which they were asked whether they had set up an endometriosis clinic (or an initiative of the same kind) and how they organise the care for individuals with (a suspicion of) endometriosis.

4.1 Endometriosis-related hospital admissions in Belgium (2016-2020)

4.1.1 Introduction

For this section, the TCT data (see Box 5) of 2016 - 2020 were used. **Only hospital admissions with ICD-10-BE code N80 (i.e. endometriosis) as principal diagnosis or any of the recorded secondary diagnoses^{kk} were extracted for analysis.** Hence, hospital admissions during which endometriosis care was offered, but not recorded with N80 as principal diagnosis or any of the recorded secondary diagnoses, are not included in the data.

^{kk} Secondary diagnoses are 'conditions that coexist at the time of admission, that develop subsequently, or that affect the treatment received and/or length of stay' according to the ICD-10-CM Official Guidelines for Coding and Reporting. Diagnoses referring to an earlier period and unrelated to the

current hospital stay are not recorded. Importantly, the codification rules stipulate that for male patients 'N80' is not accepted as a principal diagnosis, only as a secondary diagnosis.¹⁴⁴



Stays of citizens who are not entitled to reimbursements from the National Institute for Health and Disability Insurance (RIZIV – INAMI; approximately 3.8%^{II}) were included in the analysis of the clinical data but could not be studied in the analysis of billing data. Because the recording of a diagnosis is not mandatory in case of emergency room admissions without subsequent hospital admission, these admissions were discarded from the original extraction, as they may provide a biased view.

Currently, there are **no codes in the fee schedule^{mm} dedicated for procedures performed in women with (a suspicion of) endometriosis** in the Belgian ambulatory settingⁿⁿ. In addition, there is no diagnostic information in the routinely collected Belgian ambulatory data. Therefore, endometriosis care outside the hospital (e.g. by general practitioners, gynaecologists, physiotherapists) could not be assessed. A possible approach would have been the linkage of the TCT data with billing data from the outpatient setting at the level of the patient, to describe health service use in the years preceding an endometriosis-related hospitalisation. Yet, this approach would then be restricted to those women who had a hospital admission related to endometriosis in 2016-2020, hence missing women with (a suspicion of) endometriosis who did not seek care in a hospital. In addition, this would have necessitated the approval of the Sector Committee of Social Security and of Health (Health Section) of the Belgian Privacy Commission^{oo}, and would have resulted in some delay. Given the time constraints of the present report, this linkage was not considered feasible.

This is a limitation of the present study: **only endometriosis-related care provided during inpatient and day care** were considered, which most likely resulted in an over-representation of patients with more severe

disease and/or more severe symptoms. The data presented in this section should thus not be seen as prevalence data.

Last, also the calculation of direct (medical and nonmedical) and indirect costs related to endometriosis care, was considered out of scope.

Box 5 – TCT data

For each patient seen in a Belgian hospital (inpatient and day care), hospitals have to send twice a year **discharge data** (also known as 'Minimal Hospital Data', **MZG – RHM^{pp}**) to the Federal Ministry of Health (FOD – SPF).^{145, 146} The discharge data are based on the Belgian modification of the World Health Organization's Tenth Revision, International Classification of Diseases (ICD-10-CM and ICD-10-PCS), i.e. ICD-10-BE.^{144, 147}

For each hospital admission and for each specialism, one principal diagnosis and none, one or more secondary diagnoses are registered.¹⁴⁸ The principal diagnosis mentioned in the MZG – RHM mainly determines in which **Major Diagnostic Category (MDC)** a stay is classified. If the MZG – RHM data contain a procedure that is recognized by the grouper software as surgical, the respective stay will be labelled 'surgical'. Else, the stay will be classified as a medical stay.

The surgical stays are then further classified in a surgical **All Patient Refined Diagnosis Related Group (APR-DRG)**, mainly on the basis of the procedure code mentioned in the MZG – RHM. For medical stays, the principal diagnosis mainly determines in which medical APR-DRG a stay is classified.

^{II} Examples of citizens who are not entitled to a reimbursement by RIZIV – INAMI are: citizens in social welfare, citizens with no healthcare coverage in Belgium, but covered by healthcare contracts with foreign care providers or by a healthcare insurance from a European institution.

^{mm} In Belgium the fee schedule is known as 'de nomenclatuur' or 'la nomenclature'.

ⁿⁿ The ambulatory setting refers to office-based services provided in a physician's consulting room or office (i.e. not in a full operating theatre facility), which can be outside or inside the hospital premises.

^{oo} Sectoraal comité van de Sociale Zekerheid en van de Gezondheid, afdeling gezondheid/Comité sectoriel de la Sécurité Sociale et de la Santé, section santé.

^{pp} MZG – RHM: Hospital discharge data ('Minimale Ziekenhuis Gegevens'/'Résumé Hospitalier Minimum')



In order to define medically coherent and cost homogeneous groups, the APR-DRG system also comprises information on the severity of illness (SOI) and risk of mortality (ROM) of the patient during the respective hospital stay. Within each APR-DRG there are four grades of SOI: 1 = minor; 2 = moderate; 3 = major; 4 = extreme. Patients are allocated to an APR-DRG-SOI group on the basis of principal diagnosis, secondary diagnoses and procedures, age and sex of the patient and, for some APR-DRGs (e.g. burns), the type of discharge. The risk of mortality (ROM) is ranked as low, medium, high, and extreme.^{149, 150}

In addition to the hospital discharge data, **hospital billing data** with information about the administered care and the related tariff (e.g. diagnostic and therapeutic procedures, pharmaceuticals and implants, lump sum payments) have to be sent to the National Institute for Health and Disability Insurance (RIZIV – INAMI).

Each year, the Technical Cell links the **discharge data** with the **hospital billing data** at the level of each hospital stay (inpatient and day care). This linked dataset is hereinafter called **TCT data**.

4.1.2 Results at the national level

In 2016 – 2020, 46 904 hospital admissions of women^{qq} were related to endometriosis (Table 1). This selection corresponds to a rate of 162.0 admissions per 100 000 women, which is lower than the rate observed in Australia in 2016-2017 (i.e. 281.0).¹⁵¹ For about half of the endometriosis-related hospital admissions in Belgium, endometriosis was recorded as the principal diagnosis^{rr} (50.9%). Almost three in four were inpatient stays (72.5%); this breakdown is also observed within the two diagnosis subgroups (Table 19, Appendix 3.1). From 2016 to 2019, the overall numbers as well as the partitions between day-care and inpatient stays and between principal and secondary diagnosis remained more or less stable. In 2020, a marked dip is observed in the total number of stays and the rate, due to the COVID-19 pandemic^{ss}.

More details on the classification of endometriosis-related hospital admissions is provided in Appendix 3.1 (Table 20 - Table 22).

^{qq} Because the codification rules stipulate that 'N80' is not accepted as a principal diagnosis for male patients, it was decided to exclude seven hospital admissions with endometriosis as a secondary diagnosis for men.

^{rr} Endometriosis recorded as the principal diagnosis, i.e. hospital admissions with endometriosis as principal diagnosis, which may or may not have endometriosis as secondary diagnosis. Endometriosis recorded as (one of

the) secondary diagnosi(e)s, i.e. hospital admissions with endometriosis as a secondary diagnosis only (i.e. the principal diagnosis is not N80).
^{ss} Just like in many countries, regular medical and non-urgent elective surgical care was cancelled or postponed in Belgium, in order to free care capacity for the rising number of COVID-19 patients.¹⁵²


Table 1 – Number and rate of endometriosis-related hospital admissions in 2016-2020

	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
Number of stays*	9 674 (100%)	9 363 (100%)	9 677 (100%)	10 093 (100%)	8 097 (100%)	46 904 (100%)
Type of diagnosis						
Principal diagnosis	4 951 (51.2%)	4 715 (50.4%)	4 997 (51.6%)	5 047 (50.0%)	4 146 (51.2%)	23 856 (50.9%)
Secondary diagnosis	4 723 (48.8%)	4 648 (49.6%)	4 680 (48.4%)	5 046 (50.0%)	3 951 (48.8%)	23 048 (49.1%)
Type of stay						
Day-care	2 671 (27.6%)	2 394 (25.6%)	2 570 (26.6%)	2 844 (28.2%)	2 416 (29.8%)	12 895 (27.5%)
Inpatient	7 003 (72.4%)	6 969 (74.4%)	7 107 (73.4%)	7 249 (71.8%)	5 681 (70.2%)	34 009 (72.5%)
Rate of admissions per 100 000 women[§]	168.5	162.4	167.1	173.5	138.7	162.0

*: after exclusion of emergency admissions; §: principal diagnosis and secondary diagnosis combined, based on 46 904 stays recorded for women. The denominator of the rate is the mid-year Belgian female population (i.e. the average of the number of women on the first January of year Y and year Y+1; Source: Statbel, the Belgian statistical office⁸¹).

Most commonly affected age groups

More than three out of four (N=36 374, 77.5%) **endometriosis-related hospital admissions** were recorded in **women aged 15-49 years old**, i.e. in their reproductive years (Figure 4). The proportion in the group 15-44 was lower than what was observed in Australia (61.6% versus 79%) in 2016-2017.¹⁵¹ In this age group, the number of admissions with endometriosis as principal diagnosis was markedly higher than the number of admissions with endometriosis as one of the secondary diagnoses.

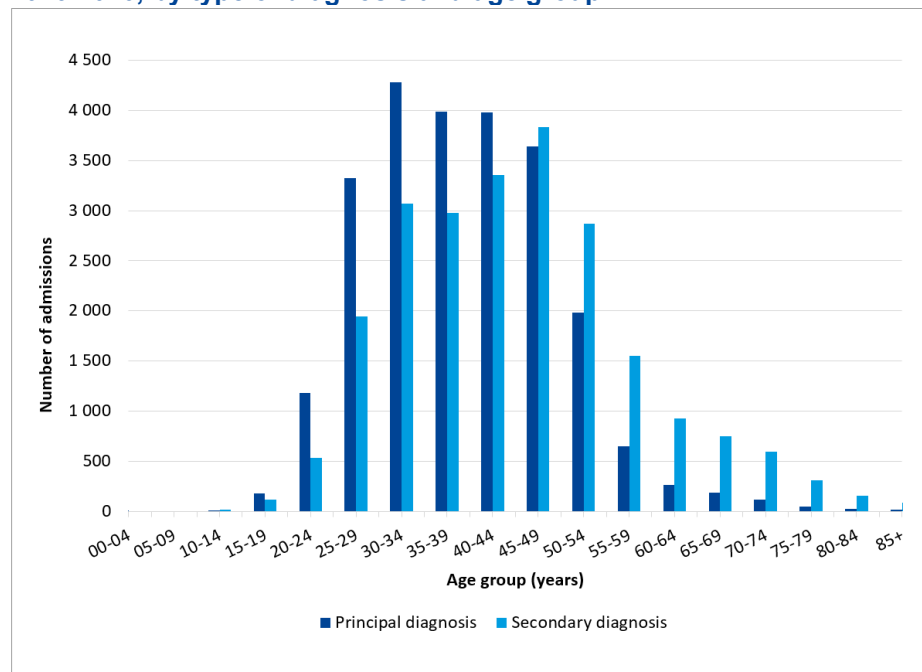
The highest number of endometriosis-related hospital admissions was observed in the age-groups 45-49 (N=7 468) and 30-34 (N=7 350), with respective rates of 389.2 and 400.4 per 100 000 women. The highest rate was observed in the group 40-44 years (401.8 per 100 000 women; N=

7 331). For hospital admissions with endometriosis as the principal diagnosis, the highest number was recorded for women aged 30-34 (N=4 277; Table 23), while for admissions with endometriosis as a secondary diagnosis only, this was the case for the age group 45-49 (N=3 828; Table 24).

The number of endometriosis-related hospital admissions in girls aged 0-14 years is negligible. Beyond the age of 49 years, the number of admissions with endometriosis as principal diagnosis as well as one of the secondary diagnoses decreases, which corresponds with the decrease in endometriosis symptoms among many women after menopause.¹⁵³



Figure 4 – Number of endometriosis-related hospital admissions in 2016-2020, by type of diagnosis and age group



Subtypes of endometriosis^{tt}

Of all hospital admissions with endometriosis as principal diagnosis, the most frequently observed was **endometriosis of the uterus** (N80.0, 40.8%), followed by endometriosis of the **ovary** (N80.1, 23.7%) and endometriosis of the **pelvic peritoneum** (N80.3, 17.4%; Figure 5 and Table 26 in Appendix 3.1). This was somewhat different in Australia, where endometriosis of the pelvic peritoneum was most commonly recorded (47%), followed by endometriosis of the uterus (19%) and the ovary (14%).¹⁵¹ For a correct interpretation of the data, it is important to mention that the code 'Endometriosis of uterus' (ICD-10-BE code N80.0) also includes adenomyosis, which shares a number of clinical features with endometriosis and often coexists in the same patient,¹⁵⁴ but which is nevertheless considered a different entity in clinical practice.⁴⁸ The location was unspecified in 11% of the admissions recorded in Australia,¹⁵¹ while the respective proportion for Belgium was only 1.8%.

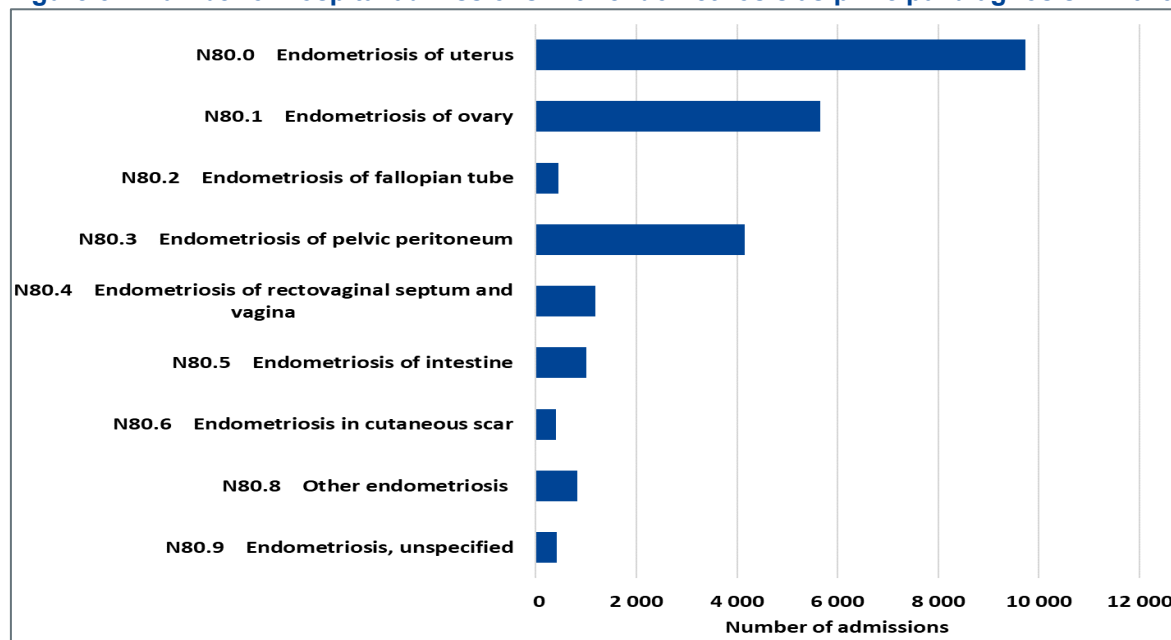
The results for hospital admissions with endometriosis as a secondary diagnosis only are presented in Table 27 (in Appendix 3.1), yet for a correct interpretation it is important to keep in mind that more than one secondary diagnosis (e.g. of endometriosis) can be registered for a hospital admission (Box 5).

^{tt} For 2016-2020, the ICD data are limited to the 4 digit coding (e.g. N80.0, N80.1), in which the code 'Endometriosis of uterus' (ICD-10-BE code N80.0) also includes adenomyosis. From 1 January 2024 onwards, hospitals have to use the 2023 version of ICD-10-BE codes including letters as fourth digit to specify new sites formerly coded under N80.8 'Other endometriosis' (i.e.: A: bladder and ureters, B: cardiothoracic space, C: abdomen and D: pelvic

nerves) and extensions of the codes until six digits to take depth into account. This new version will make it possible to distinguish e.g. patients admitted in hospital with adenomyosis of the uterus (code N80.03) from patients admitted with endometriosis of the uterus, unspecified (N80.00), superficial endometriosis of the uterus (N80.01), and deep endometriosis of the uterus (N80.02).



Figure 5 – Number of hospital admissions with endometriosis as principal diagnosis in 2016-2020, by ICD-10-BE code and type of diagnosis



Notes: The code 'Endometriosis of uterus' (ICD-10-BE code N80.0) also includes adenomyosis, which shares a number of clinical features with endometriosis and often coexists in the same patient,¹⁵⁴ but which is nevertheless considered a different entity in clinical practice;⁴⁸ N80.8 includes endometriosis of the thorax.



Length of stay for patients admitted in hospital for endometriosis

Of all hospitalisations for endometriosis, 72.5% were inpatient stays, with a mean length of stay of around three days (Table 2). Almost one in ten inpatient stays (9.5%) lasted five or more days; this proportion was lower when endometriosis was recorded as principal diagnosis (6.8%), than when endometriosis was recorded as one of the secondary diagnoses (12.2%).

Table 2 – Length of stay for endometriosis-related hospital admissions, 2016-2020

	All hospital admissions for endometriosis N (%)	Hospital admissions with endometriosis as the principal diagnosis N (%)	Hospital admissions with endometriosis as a secondary diagnosis only N (%)
Day care	12 895 (27.5%)	6 270 (26.3%)	6 625 (28.7%)
Inpatient			
1–2 days	20 733 (44.2%)	12 010 (50.3%)	8 723 (37.9%)
3–4 days	8 841 (18.9%)	3 950 (16.6%)	4 891 (21.2%)
5–6 days	2 466 (5.3%)	1 030 (4.3%)	1 436 (6.2%)
7+ days	1 969 (4.2%)	596 (2.5%)	1 373 (6.0%)
Total	46 904 (100%)	23 856 (100%)	23 048 (100%)
Length of stay, excluding day care admissions			
N	34 009	17 586	16 423
Mean, SD (days)	2.9 (4.0)	2.4 (2.8)	3.4 (4.9)
Median, Q1-Q3 (days)	2 (1-3)	2 (1-3)	2 (1-4)



The differences mentioned in the preceding paragraphs between the Belgian (2016-2020) and Australian (2016-2017) data may be due to differences in prevalence of endometriosis, in health seeking behaviour, differences in clinical management, differences in application rules of the fee schedule, differences in registration practices, but also the inclusion of the 2020 data for Belgium, which pulled down the overall number of endometriosis-related admissions.

Procedures undertaken during endometriosis-related hospital admissions

For the following sections, only procedures from four sub-articles of Article 14 of the fee schedule (i.e. gynaecologic surgery (art. 14 g), abdominal surgery (art. 14 d), urologic surgery (art. 14 j), and thoracic surgery (art. 14 e) were selected as these were considered possibly involved in endometriosis surgery (Table 29). Note that the (sub-)totals reported in this section are lower compared to the totals reported in the previous section, as not for all endometriosis-related stays a linkage was possible with the billing data.

The interpretation of the results of this and the following sections should be done in view of the ongoing application rules of the fee schedule (Box 6), which stipulate – among others – that during the same surgical session in the same ‘surgical region’, only the main procedure (i.e. for which the highest remuneration is provided) is remunerated.¹⁵⁵ Hence, only the main procedure can be identified in the hospital billing data.

Therefore, these results are not compared with the information obtained from other countries, like Australia, where for instance more than one procedure can be recorded during endometriosis-related hospitalisations according to the Australian Classification of Health Interventions system (ACHI).¹⁵¹ Furthermore, a mapping between the ACHI and the ICD-10-BE procedures system (based on the US ICD-10-PCS system) as used in the Belgian TCT data, was considered out of scope for the present study.

The results for 2016-2020 indicate, that in 76.3% of all endometriosis-related admissions a surgical procedure was recorded (Table 3); this proportion was somewhat higher when endometriosis was recorded as principal diagnosis

(83.5%) and thus lower when it was recorded as secondary diagnosis (68.7%).

Table 3 – Number endometriosis-related hospital admissions in 2016-2020, by type of stay

	Surgical N (%)	Medical N (%)	Total N (%)
Number of stays*	34 233 (76.3%)	10 657 (23.7%)	44 890 (100%)
Type of diagnosis			
Principal diagnosis	19 079 (83.5%)	3 760 (16.5%)	22 838 (100%)
Secondary diagnosis	15 154 (68.7%)	6 897 (31.3%)	22 044 (100%)

**: after exclusion of emergency admissions; the totals reported in this table are lower compared to the totals reported in Table 2, as not for all stays a linkage was possible between discharge data and billing data.*

Box 6 – Application and interpretation rules of the fee schedule

Within the fee schedule, several application rules have been developed over the years:

- All procedures listed in the sub-articles a) to m) of Article 14 of the fee schedule which cover general surgery, neurosurgery, plastic surgery, abdominal surgery, thoracic surgery, vascular surgery, gynaecology and obstetrics, ophthalmology, otorhinolaryngology, urology, orthopaedics, stomatology and transplant surgery) ‘are in any case considered to be related’. The long and the short of it is that **all medical specialties involved in these procedures may use each other’s codes**, apart from some exceptions. In practice, this means that a general surgeon may perform a hysterectomy (included in chapter 14 g, gynaecology and obstetrics), and that a gynaecologist may perform a mastectomy (included in chapter 14 e, thoracic surgery).



- In case more than one surgical procedure is performed in the same 'surgical region' during the same surgical session, **only the main procedure will be remunerated**. In case of gynaecological procedures, the same 'surgical region' applies to all surgical procedures that are performed 'through the same access route' (specified in an interpretation rule of art. 14g).
- In case more than one surgical procedure is performed during the same surgical session, but in **various 'surgical regions'**, then the **main procedure** will be remunerated at **100%** and the other procedure(s) at **50% of the original rate**, unless the description of the surgical procedure or the fee schedule rules provide otherwise.
- For **surgical assistance** during surgical procedures with a relative value that is equal to or greater than K 120 or N 200*, the fee is reduced to **10%** of the original rate, regardless of the skill of the physician assisting during the procedure. Hence, in case of a multidisciplinary surgical approach of e.g. (deep) endometriosis, which necessitates e.g. a hysterectomy with colon resection, which is collectively performed by a gynaecologist and abdominal surgeon, only the colon resection (for which the highest remuneration is provided) can be charged at 100% by one of the two specialists and at 10% for the assisting specialist. Together they receive thus 110% of the fee for the colon resection. The hysterectomy and possible other procedures in the same 'surgical region' are not remunerated.

**: Procedures covered by compulsory health care insurance are listed in a fee schedule, which contains for each item the professional qualification needed to be eligible for reimbursement, a code-number, a description of the item, a key letter according to the medical specialty, a coefficient and application rules. The coefficient gives for each procedure the relative value compared to other procedures with the same key letter. Multiplying the coefficient by the value of the key letter determines the amount of payment to the provider concerned (i.e. the fee).*

Source: Royal Decree of 14 September 1984 setting the RIZIV – INAMI nomenclature of health care for the compulsory health care and allowances insurance;¹⁵⁶ and RIZIV – INAMI, 2017 & 2021.^{155, 157}

In case of a hospital admission with endometriosis as the principal diagnosis, the most frequently recorded surgical procedures were 'Ovarian cystectomy with or without ovarioplasty, with anatomopathological confirmation' (432596 – 432600; 18.4%), 'Diagnostic hysteroscopy with or without biopsy or cytology, with protocol' (432390 – 432401; 17.5%), and 'Total hysterectomy by laparoscopic route, with anatomopathological confirmation' (432736 – 432740; 15.7%; Table 28).

In case of endometriosis as one of the secondary diagnoses, the top three was slightly different with on top 'Total hysterectomy by laparoscopic route, with anatomopathological confirmation' (432736 – 432740; 21.7%), followed by 'Diagnostic hysteroscopy with or without biopsy or cytology, with protocol' (432390 – 432401; 13.0%) and 'Total hysterectomy, by vaginal route, including front colporrhaphy and/or possible posterior colpoperineorrhaphy' (431314 – 431325; 11.8%).

Medical specialists involved during hospital admissions with endometriosis as principal diagnosis

Here, procedures were assigned to a medical specialty based on the qualification code of the medical specialist who was remunerated for the surgical intervention during the endometriosis-related hospital stay (Table 4).

Gynaecologists were involved in the vast majority (96.3%) of hospital stays with endometriosis as principal diagnosis during which surgery was performed. Also general surgeons (8.7%) and urologists (6.2%) were remunerated during these stays.



Table 4 – Number of hospital admissions with endometriosis as a principal diagnosis and a surgical intervention in 2016-2020, by qualification code of the principal remunerated medical specialist during the admission

	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	2016-2020 N (%)
Gynaecologist (qualification code starting with 34)	3 793 (96.6%)	3 561 (95.9%)	3 887 (96.1%)	3 902 (96.3%)	3 233 (96.7%)	18 376 (96.3%)
General surgeon (qualification code starting with 14)	307 (7.8%)	306 (8.2%)	372 (9.2%)	380 (9.4%)	290 (8.7%)	1 655 (8.7%)
Urologist (qualification code starting with 45)	242 (6.2%)	241 (6.5%)	253 (6.3%)	240 (5.9%)	208 (6.2%)	1 184 (6.2%)
Other	15 (0.4%)	16 (0.4%)	17 (0.4%)	15 (0.4%)	7 (0.2%)	70 (0.4%)
Total	3 925	3 714	4 043	4 052	3 342	19 076*

*: The linkage of the 23 856 admissions with endometriosis as principal diagnosis was successful in 22 839 hospital admissions (96.3%, reflecting approximately 3.6% of women not covered by the compulsory health care insurance and 0.1% data flaws) and a surgical intervention was billed in 19 079 of them. Three stays with only qualification codes referring to specialists in training were excluded from the analyses.

Readmissions after a hospital stay with endometriosis as principal diagnosis during which a surgical procedure was recorded

In this section the stays per patient were counted. Hence, the analyses are performed on a patient level, not on a stay level, which explains the differences in total numbers compared to the previous section. The hospital billing data indicate that in 2016-2020, a surgical procedure was recorded during the index admission of 17 532 patients of a total of 20 559 patients (85.3%) who were admitted in hospital with endometriosis as principal diagnosis. In 12.6% (n=2 211) of the 17 532 operated patients, a readmission with endometriosis as principal or secondary diagnosis was identified in the years following the 'index year'^{uu} (Table 5). In three out of

four of these patients (77.1%), the number of readmissions was confined to one, and in the majority of these 'single' readmissions (1 341/1 704=78.7%, data not presented), the principal diagnosis was again endometriosis.

These results should be interpreted with caution as the follow-up period decreases over time. The data for 2016 give the best indication of the 5-year readmission rate.

In 10% of women who were admitted in hospital with endometriosis as principal diagnosis and during which a surgical procedure was recorded, an additional surgical procedure was recorded during the readmission (Table 30).

^{uu} The index year is the first year for which a hospital stay with surgical intervention is recorded for a patient. It cannot be ruled out that this index procedure is actually a readmission following a stay recorded before 2016 (i.e. before the data extraction period).



Table 5 – Readmissions (surgical and non-surgical) per patient after a stay in hospital with endometriosis as principal diagnosis and during which a surgical procedure for endometriosis was recorded

Index year*	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
Number of readmissions						
0	3 104 (81.5%)	2 915 (84.7%)	3 202 (86.9%)	3 289 (90.6%)	2 811 (94.8%)	15 321 (87.4%)
1	493 (12.9%)	391 (11.4%)	388 (10.5%)	294 (8.1%)	138 (4.7%)	1 704 (9.7%)
2	154 (4.0%)	84 (2.4%)	65 (1.8%)	41 (1.1%)	13 (0.4%)	357 (2.0%)
3	36 (0.9%)	34 (1.0%)	14 (0.4%)	5 (0.1%)		89 (0.5%)
4+ (max: n=16)	23 (0.6%)	18 (0.5%)	15 (0.4%)	3 (0.1%)	2 (0.1%)	61 (0.4%)
Total number of patients	3 810 (100%)	3 442 (100%)	3 684 (100%)	3 632 (100%)	2 964 (100%)	17 532 (100%)

*: Index year refers to the first year for which a hospital stay with surgical intervention is recorded for a patient.

Complications within thirty days after hospital stays with endometriosis as principal diagnosis and during which a surgical procedure was recorded

In the fee schedule there are no codes formally dedicated to complications, hence a proxy approach was indicated to estimate the number of complications after surgery for endometriosis. For these analyses, readmissions until thirty days after discharge from a hospital stay with endometriosis as principal diagnosis and during which a surgical procedure was recorded, were selected based on the ICD-10-BE principal diagnosis codes (Table 31 in Appendix 3.1). These readmissions were considered related to the preceding endometriosis surgery in case the principal diagnosis code referred to endometriosis, surgical aftercare, intra-abdominal or urinary infection, hydronephrosis, adjustment of urinary device, unspecified abdominal pain or postprocedural hematoma; the complete list of ICD-10-BE principal diagnosis codes is provided in Table 31, Appendix 3.1.

In 2016-2020, 108 women (0.6%) were readmitted in hospital for a complication within thirty days after discharge of a hospital stay with endometriosis as principal diagnosis and during which a surgical procedure was recorded (Table 6). In about half of these patients a surgical procedure was performed during a readmission. More than one readmission for complications within thirty days after discharge was rarely observed.

**Table 6 – Complications (surgical and non-surgical) per patient within thirty days after a stay in hospital with endometriosis as principal diagnosis and during which a surgical procedure for endometriosis was recorded**

Index year	2016	2017	2018	2019	2020	Total
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Number of readmissions						
0	3 775 (99.1%)	3 416 (99.2%)	3 671 (99.6%)	3 610 (99.4%)	2 949 (99.5%)	17 421 (99.4%)
1	33 (0.9%)	25 (0.7%)	13 (0.4%)	22 (0.6%)	15 (0.5%)	108 (0.6%)
2	2 (0.1%)	1 (0.0%)				3 (0.0%)
Total number of patients	3 810 (100%)	3 442 (100%)	3 684 (100%)	3 632 (100%)	2 964 (100%)	17 532 (100%)

Note: surgery is based on billing data.

4.1.3 Results at the hospital level

For the following section, a total of 23 855 hospital admissions with endometriosis as principal diagnosis (both inpatient and day-care) recorded in 99 Belgian hospitals were taken into account. The 99 hospitals recorded for at least one year of the study period (2016-2020) at least one hospital admission with endometriosis as principal diagnosis^{vv}.

Box 7 – Hospital activity

Analysis by license number: Hospital identification is based on the license number provided by the Federal Public Service Health, Food Chain Safety and Environment (FOD VVVL – SPF SPSCAE), as this is the base for the registration and financing of their activity. So, even if hospitals share the same name (e.g. 'Centre Hospitalier Chrétien',

'Groupe Jolimont'), but have more than one license number, the identification is based on the license numbers (i.e. analyses as two different hospitals), and their activity is presented separately.

Also, the results are presented by hospital and not by site. As hospital sites (campuses) may change the hospital to which they 'belong', this may result in changes over time of the respective hospital activity.

Analysis by region: All activities of the CHIREC-SARE hospital (i.e. license number 710723) were attributed to Brussels where its main sites (i.e. the Clinique St-Anne and St-Rémi) are located. However, a third hospital site is located in Braine L'Alleud, in the Walloon region. As a consequence, the total hospital activity in Brussels may thus be overestimated and likewise the activity in the Walloon region underestimated.

^{vv} Note that one endometriosis-related hospital stay, which was recorded in a rehabilitation hospital, was excluded from the analysis, as it was considered out of scope.

**Table 7 – Distribution of hospital admissions with endometriosis as principal diagnosis among Belgian hospitals**

Index year	2016	2017	2018	2019	2020	Average per year 2016 - 2020	Total 2016-2020
Total number of stays	4 951	4 715	4 996	5 047	4 146	4 771	23 855
Minimum	1	0	1	1	0	0.8	4
Q1	13	13	14	14	11	13.4	67
Median	27	29	27	29	22	26	130
Q3	57	54	58	58	48	57.2	286
Maximum	410	459	523	543	394	309.2	1 546

Between 2016 and 2020, the median number of hospital admissions with endometriosis as principal diagnosis varied between 22 and 29 (Table 7). A quarter of the Belgian hospitals (Q1) recorded in these years on average not more than thirteen endometriosis-related hospital admissions per year. Another quarter of hospitals (Q3) had on average at least 57 endometriosis-related hospital admissions per year.

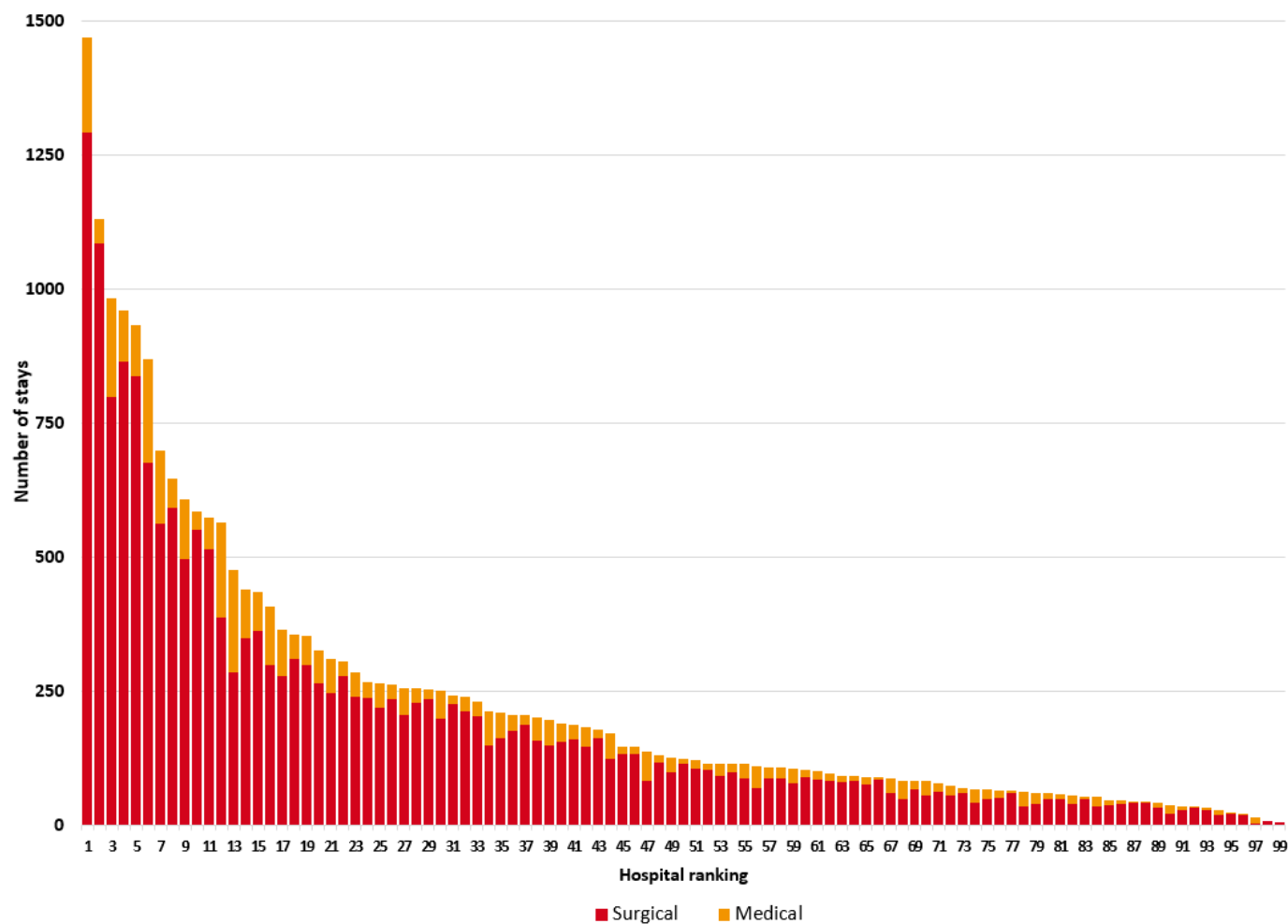
In Figure 6, the distribution of the 23 855 stays with endometriosis as principal diagnosis (2016-2020) among the Belgian hospitals is illustrated. During the five-year study period, the number of stays ranged from four to 1 546 stays per hospital. In all but one hospital, a surgical procedure is recorded in the majority (55% - 100%) of hospital admissions with endometriosis as principal diagnosis. In the remaining hospital, in only two out of thirteen stays (15%) with endometriosis as principal diagnosis, surgery was recorded.

During the study period, the top-10 hospitals (with regard to endometriosis as principal diagnosis) collectively recorded 9 324 hospital admissions with endometriosis as principal diagnosis, or in other words 39.1% of the total number of such admissions in 2016-2020. In these ten hospitals, the proportion of stays with endometriosis as the principal diagnosis during which a surgical procedure was recorded, ranged between 78% and 96%. Of the top-10 hospitals, three are located in the Flemish region (northern region), one in Brussels (capital region) and six in the Walloon region (southern region).

Comparable data for hospital admissions with endometriosis as principal diagnosis as well as endometriosis as one of the secondary diagnosi(e)s are provided in Figure 12 and Table 33 (Appendix 3.2).



Figure 6 – Distribution of hospital admissions with endometriosis as principal diagnosis among Belgian hospitals, by type of admission (2016-2020)



**Key Points:**

- From 2016 to 2020, 162.0 hospital admissions per 100 000 women were related to endometriosis. In 50.9% of the endometriosis-related hospital admissions, endometriosis was recorded as the principal diagnosis;
- Overall, 77.5% of endometriosis-related hospital admissions was recorded in women of 15-49 years old;
- Of all hospital admissions with endometriosis as principal diagnosis, the most frequently observed was endometriosis of the uterus (N80.0, 40.8%), followed by endometriosis of the ovary (N80.1, 23.7%) and endometriosis of the pelvic peritoneum (N80.3, 17.4%);
- Of all hospitalisations for endometriosis, 72.5% were inpatient stays, with a mean length of stay of around three days;
- In 76.3% of all endometriosis-related hospital admissions a surgical procedure was recorded;
- In 12.6% of the 17 532 women who were admitted in hospital with endometriosis as the principal diagnosis and who had surgery during that stay, another endometriosis-related admission was recorded in the years following the 'index year';
- Less than one percent of women were readmitted in hospital for a complication within thirty days after discharge of a hospital stay with endometriosis as principal diagnosis and during which a surgical procedure was recorded;
- In 2016-2020, the median number of hospital admissions with endometriosis as principal diagnosis varied between 22 and 29; a quarter of the Belgian hospitals (Q1) recorded in these years

on average not more than thirteen endometriosis-related hospital admissions per year. Of the top-10 hospitals, three are located in the Flemish region (northern region), one in Brussels (capital region) and six in the Walloon region (southern region).

- The currently available data on endometriosis care are limited.

4.2 How is care for individuals with endometriosis currently organised in the Belgian hospitals?

To date, there are **no certified endometriosis clinics or centres of expertise for endometriosis in Belgium**. Nevertheless, there are several hospitals that have established endometriosis clinics, following e.g. examples from abroad. As these bottom-up initiatives are not officially recognised, there are no data available on their actual number, nor on their functioning. Therefore, a questionnaire was developed to map these initiatives and to get a view of the organisation of care for individuals with (a suspicion of) endometriosis offered in Belgian hospitals.

4.2.1 Methods

The questionnaire was distributed on 21 September 2023 to all Belgian hospitals^{ww} (n=101) via the medical and general directors. They were asked to forward the mail with a link and password to the online questionnaire (in French and Dutch), to the medical specialist working in their hospital with the highest level of expertise in endometriosis management (e.g., the head of the endometriosis clinic, the head of the gynaecology department). To maximise the response rate, the initial deadline was postponed from 8 to 15 October 2023.

Participants were asked about the organisation and functioning of endometriosis care in their hospital and about ways to improve endometriosis care in Belgium. The Dutch and French versions of the

^{ww} By hospital, we mean each institution or group of institutions with the same licensing number.



questionnaire are provided in Appendix 4.1 and Appendix 4.2. Descriptive statistics (frequencies and proportions) were used to report the results.

4.2.2 General information

We received a response of 80 hospitals (79.2% of the total number of hospitals), of which 77 completed the survey (response rate: 76.2%; see Table 8). The list of participating hospitals is provided in Appendix 4.4, Table 34). Three hospitals indicated that they do not have an endometriosis clinic and they did not complete the survey; these hospitals are not included in the further discussion and analysis.

Of the 77 hospitals that completed the survey, 30 (39.0%) indicated that they had an endometriosis clinic. Four of these hospitals indicated that they had an endometriosis clinic on two campuses^{xx}, which are both mentioned in Table 35. The way hospitals with an endometriosis clinic organise the care for women with (suspected) endometriosis is elaborated in section 4.2.3.

In two hospitals, the professionals who filled in the survey^{yy} stated they were unsure whether their hospital had an endometriosis clinic; their results are combined with the hospitals that did not have an endometriosis clinic. The organisation of care for women with (suspected) endometriosis in hospitals without endometriosis clinics is described in section 4.2.4.

4.2.3 Hospitals with a self-reported endometriosis clinic

Half of the hospitals which reported having an endometriosis clinic is situated in Flanders; another nine are located in the Walloon region and six in the Brussels-Capital region (Table 8).

Table 8 – Regional distribution of hospitals which completed the survey, by self-reported endometriosis clinic and region (Belgium, n=77)

	Hospitals with endometriosis clinic (n=30)	Hospitals without endometriosis clinic (n=47)
Region		
Flemish region	15 (50.0%)	23 (48.9%)
Walloon region	9 (30.0%)	20 (42.6%)
Brussels-Capital region	6 (20.0%)	4 (8.5%)

Of those hospitals that reported having an endometriosis clinic, about half of the surveys were completed by the head of the endometriosis clinic (n=16, 53.3%). The other fourteen surveys were completed by the head of the gynaecology service (n=11, 36.7%) or a gynaecologist with expertise in endometriosis (n=3, 10.0%).

The endometriosis team and multidisciplinary team (MDT) meetings

A typical endometriosis team would be made up of at least a gynaecologist (n=30, 100%), an infertility specialist (n=28, 93.3%), an abdominal surgeon (n=28, 93.3%), a radiologist (n=27, 90.0%) and a urologist (n=25; 83.3%; Table 9). But, about two in three endometriosis clinics also have a pain specialist, a psychologist, a physiotherapist and/or a sexologist in the endometriosis team. In addition, half of the endometriosis clinics have someone in charge of coordination and continuity of care^{zz}. This task is most often performed by a gynaecologist (n=11, 73.3%) and/or a nurse/specialist nurse (n=6, 40.0%).

^{xx} In case respondents replied that their hospital had more than one campus, they were asked to focus in the survey on the campus with which they are most familiar and about which they can provide the most accurate information. The potential collaboration between campuses of the same hospital was considered out of scope in this survey.

^{yy} For these hospitals the survey was completed by the medical director and a gynaecologist with expertise in endometriosis.

^{zz} Multiple answers were possible for this question, hence the various subtotals may add up to >100%.

**Table 9 – Specialties within the endometriosis team and within the MDT**

Specialty*	Endometriosis team (n=30)	MDT (n=23)
Gynaecologist	30 (100%)	23 (100%)
Abdominal surgeon	28 (93.3%)	20 (87.0%)
Infertility specialist	28 (93.3%)	18 (78.3%)
Radiologist	27 (90.0%)	19 (82.6%)
Urologist	25 (83.3%)	10 (43.5%)
Pain specialist	22 (73.3%)	7 (30.4%)
Psychologist	21 (70.0%)	9 (39.1%)
Physiotherapist	19 (63.3%)	3 (13.0%)
Sexologist	19 (63.3%)	3 (13.0%)
Pathologist	15 (50.0%)	4 (17.4%)
Dietician	11 (36.7%)	1 (4.3%)
Specialist nurse	8 (26.7%)	8 (34.8%)
Midwife	8 (26.7%)	3 (13.0%)
Thoracic surgeon	8 (26.7%)	1 (4.3%)
Nurse	7 (23.3%)	4 (17.4%)
Physical medicine specialist	7 (23.3%)	1 (4.3%)
Specialist midwife	4 (13.3%)	4 (17.4%)
Social worker	4 (13.3%)	1 (4.3%)
Psychiatrist	2 (6.7%)	0
Other professions †	7 (23.3%)	4 (17.4%)

MDT: multidisciplinary team; *: multiple answers were possible for this question; †: "other professions" mentioned in the endometriosis team or MDT were: echo-endoscopist, ultrasound specialist (gynaecology), secretary, osteopath (specialism open for physicians and physiotherapists, that is currently not officially recognized in Belgium), acupuncturist (not officially recognized in Belgium), sophrologist (not officially recognized in Belgium), specialist pain nurse, nutritherapist (not officially recognized in Belgium) and data manager.

Importantly, seven of the thirty hospitals with an endometriosis clinic (23.3%) reported that they do not organise multidisciplinary team (MDT) meetings to discuss the management of patients with (suspected) endometriosis. As the organisation of MDT meetings is considered an essential element in the multidisciplinary approach of endometriosis expert centres (cf. section 5.3), yet not remunerated for endometriosis, the main results of this section are also presented separately for hospitals that do and do not organise MDT meetings for endometriosis (Table 36).

In the hospitals that do have MDT meetings, the gynaecologist is accompanied in four out of five MDTs by an abdominal surgeon, an infertility specialist and a radiologist (Table 9).

Few self-reported endometriosis clinics discuss all patients with (suspected) endometriosis during MDT meetings (n=4, 17.4%; Table 10). Eleven endometriosis clinics (47.8%) discuss all patients for whom surgery is planned, of which seven also discuss patients with infertility problems due to (suspected) endometriosis. In six clinics (26.1%), only patients with planned surgery for deep endometriosis are discussed, whereas one clinic discusses all patients with planned surgery for deep endometriosis and fertility problems. One clinic only discusses very complex cases.

**Table 10 – Type of patients discussed during MDT meetings**

	Number of endometriosis clinics (n=23)
All patients with (suspected) endometriosis	4 (17.4%)
Only patients with (suspected) endometriosis for whom surgery is planned	4 (17.4%)
Only patients with (suspected) deep endometriosis for whom surgery is planned	6 (26.1%)
Patients for whom surgery is planned and patients with fertility problems	7 (30.4%)
Patients for whom surgery for deep endometriosis is planned and patients with fertility problems	1 (4.3%)
Other [#]	1 (4.3%)

[#]: 'only very complex cases'

Waiting times and case load

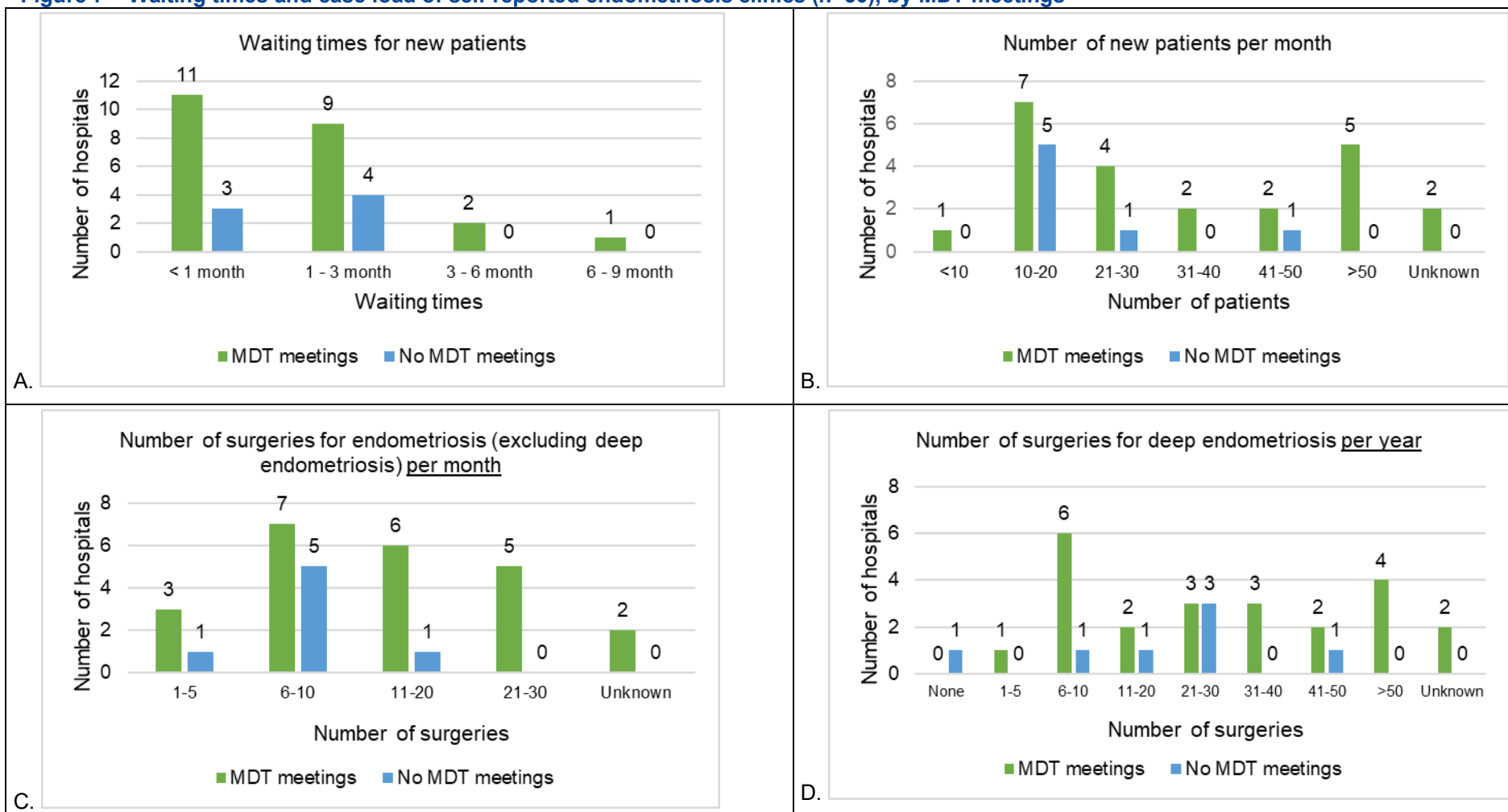
Nine out of ten hospitals with an endometriosis clinic said the waiting time for new patients was less than three months. Of these, half reported a waiting time of less than one month (Figure 7A).

Seventeen endometriosis clinics see ten to thirty new patients per month, but there are extremes with less than ten patients (n=1 clinic) and more than fifty (n=5; Figure 7B, Table 36).

Overall, nineteen centres (63.3%) perform between six and twenty surgeries for endometriosis (excluding deep endometriosis) per month and another five between twenty-one and thirty. Endometriosis clinics that do not organize MDTs tend to be among the lower volume hospitals (< 10 surgeries per month; Figure 7C, Table 37). There is a large variability in the number of reported surgeries for deep endometriosis: from none (reported by an endometriosis clinic without MDT) to more than fifty (reported by four endometriosis clinics with MDT; Figure 7D, Table 36).



Figure 7 – Waiting times and case load of self-reported endometriosis clinics (n=30), by MDT meetings



MDT: multidisciplinary team; 'deep endometriosis', as defined by ESHRE, 2022.³³; for two endometriosis clinics with MDT meetings, number of new patients per months, surgeries excluding deep endometriosis and surgeries for deep endometriosis were unknown.



Referral patterns

Endometriosis clinics mainly get referrals from within the same hospital network (n=30, 100%), from general practitioners (n=29, 96.7%) and from gynaecologists working in private practice (n=25, 83.3%) but also from specialists from other hospital networks (n=20, 66.7%; Table 37). Yet, nine in ten endometriosis clinics (n= 27, 90.0%) report that they also see patients coming on their own initiative (i.e. without formal referral; n=27; 90.0%). Sixteen endometriosis clinics (53.3%) indicated that they themselves sometimes refer patients whose case is too complex; thirteen clinics reported that they refer patients to other Belgian centres with more (specific) expertise in endometriosis surgery, whereas six clinics also refer patients to experts abroad. Some examples of referred patients are: patients with severe (e.g. with bowel or ureter infiltration) or recurrent deep endometriosis, deep endometriosis with infertility, atypical lesions, or extra-abdominal endometriosis.

Recorded hospital admissions

The hospital data (TCT data, see Box 5) for the thirty hospitals that reported having an endometriosis clinic, indicated that in 2016-2020 the mean annual number of endometriosis-related hospital admissions (as principal diagnosis or as (one of the) secondary diagnosi(e)s) ranged between 2.6 and 486.8. For 9.5% to 77.3% of these admissions endometriosis was recorded as principal diagnosis.

In 2016-2020, the thirty hospitals with an endometriosis clinic, recorded each year on average 2.2 to 384.4 endometriosis-related hospital admissions during which surgery was performed. For several hospitals the number of admissions with surgery recorded in the TCT data corresponded very well with the number of surgical interventions (with and without deep endometriosis combined, cf. supra) they had reported in the questionnaire, but for others this was not the case. This discordance may be due to the fact

that hospitals were asked in the questionnaire about the current number of surgical endometriosis-related interventions, while the TCT data cover 2016-2020, including the year 2020^{ss} during which non-urgent elective surgical care was cancelled or postponed due to COVID-19. Also, the TCT data extracted for this study are confined to all admissions for which endometriosis was recorded as principal or (one of the) secondary diagnosi(e)s, hence if hospitals admitted patients with endometriosis without documenting this diagnosis, these admissions are not included in the data extraction (and therefore not in the reported TCT data).

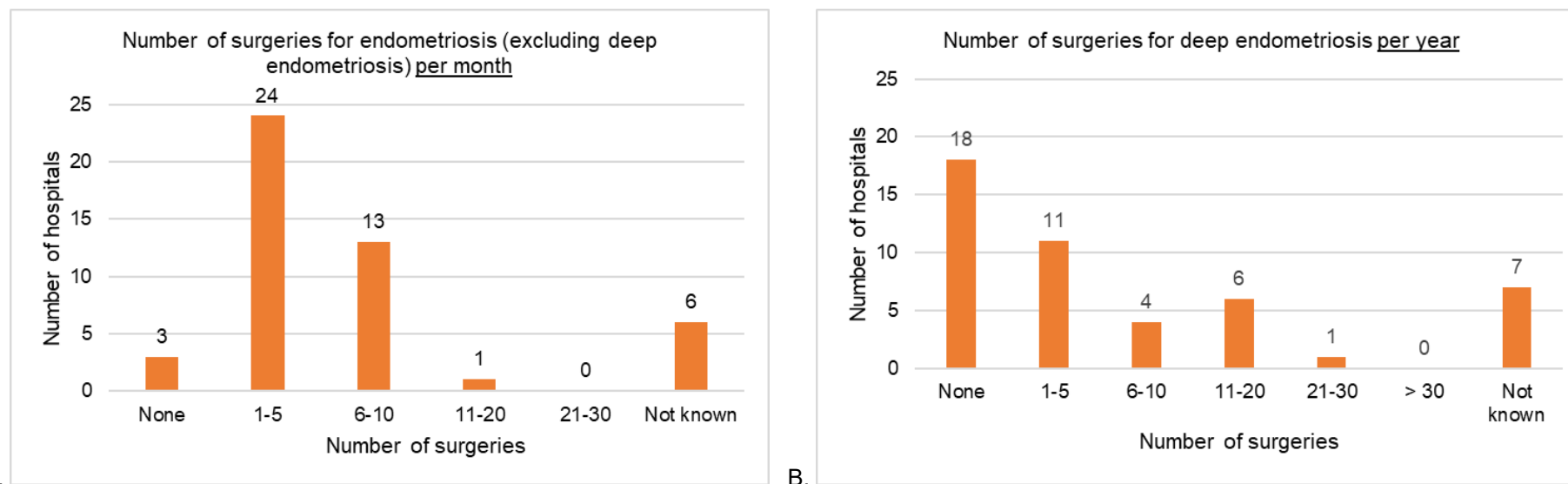
4.2.4 Hospitals without an endometriosis clinic

For the 47 hospitals without an endometriosis clinic, the survey was completed most often by the head of the gynaecology department (n=34, 72.3%).

Of these hospitals, six (12.8%) organize MDTs for patients with (suspected) endometriosis; half of these hospitals (n=3) indicated that they are planning to start an endometriosis clinic themselves, as compared to nine hospitals (9/41) that do not organize MDTs.

Surgical case load

Almost all hospitals (n=44, 93.6%) without an endometriosis clinic reported that they perform surgical procedures for (suspected) endometriosis (Figure 8A; Table 38). About half of these hospitals (n=24, 51.1%) perform on average one to five surgical procedures for endometriosis (excluding deep endometriosis) each month, while only one hospital performs more than twenty of these procedures each month. Overall, about one in two hospitals without endometriosis clinic (n=22, 46.8%) also performs surgery for deep endometriosis (Figure 8B). Half of them performs on average not more than ten of these surgeries per year (n=15, 31.9%).

**Figure 8 – Surgical case load of hospitals without endometriosis clinic (n=47)**

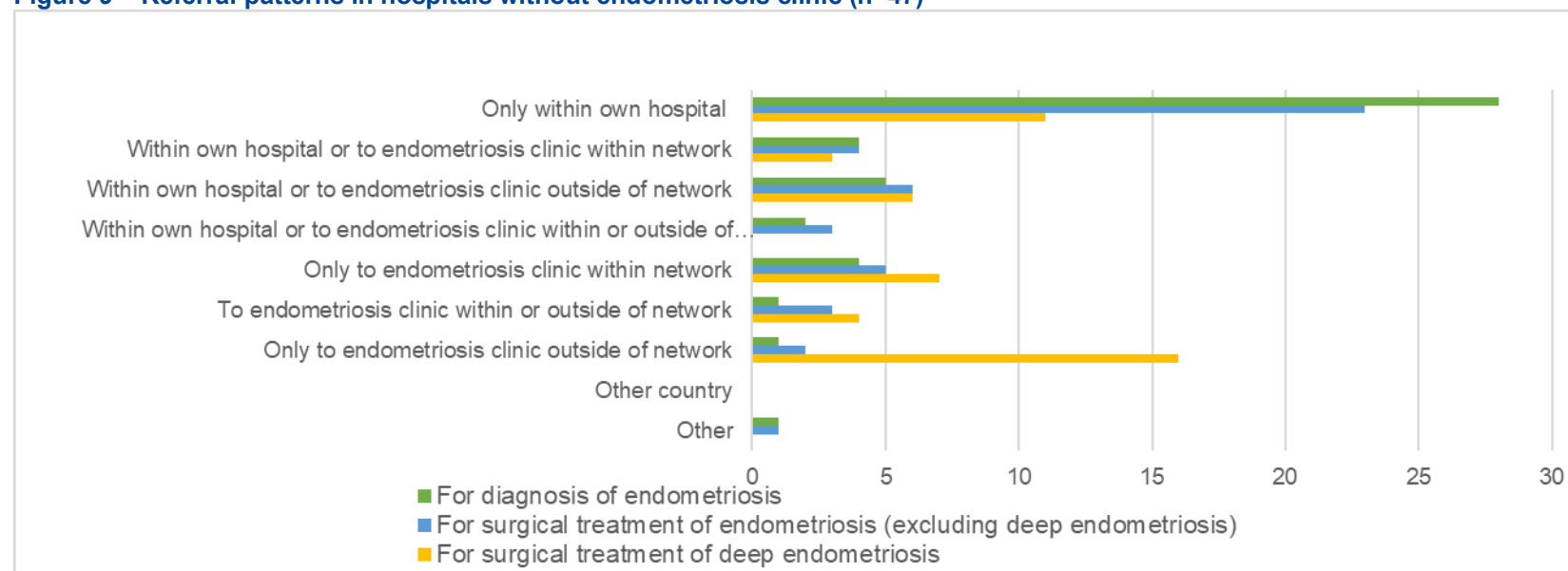
MDT: multidisciplinary team; 'deep endometriosis', as defined by ESHRE, 2022.³³

Referral patterns

When a woman with suspected endometriosis presents in a hospital without endometriosis clinic, she is often referred for **diagnosis** to a specialist (gynaecologist or radiologist) within the same hospital (n=28, 59.6%; Figure 9, Table 39). Four hospitals (8.5%) reported that they also refer to an endometriosis clinic within the network, while five hospitals (10.6%) refer within the hospital or to an endometriosis clinic within or outside their hospital network. Nine (19.1%) also refer beyond their own hospital network.

Only six respondents (12.8%) report that women with suspected endometriosis would not be referred for diagnosis within the own hospital, but to an endometriosis clinic in the same network and/or another network.

For **surgical treatment** (excluding deep endometriosis), twenty-three hospitals without an endometriosis clinic (48.9%) would refer the patient to a specialist within the same hospital (a gynaecologist with (n=16) or without (n=7) expertise in endometriosis surgery; Figure 9, Table 39). One hospital indicated that they would refer to a gynaecologist with expertise or to a general surgeon with expertise in their hospital²². Thirteen hospitals (27.7%) indicated that they refer either within their hospital or to an endometriosis clinic within their network (n=4), an endometriosis clinic outside the network (n=6) or to endometriosis clinics both within and outside the network (n=3). Only ten hospitals (21.3%) would always refer a patient for surgery to an endometriosis clinic, either within the network (n=5), outside of the network (n=2) or both (n=3).

**Figure 9 – Referral patterns in hospitals without endometriosis clinic (n=47)**

Note: 'deep endometriosis', as defined by ESHRE, 2022.³³

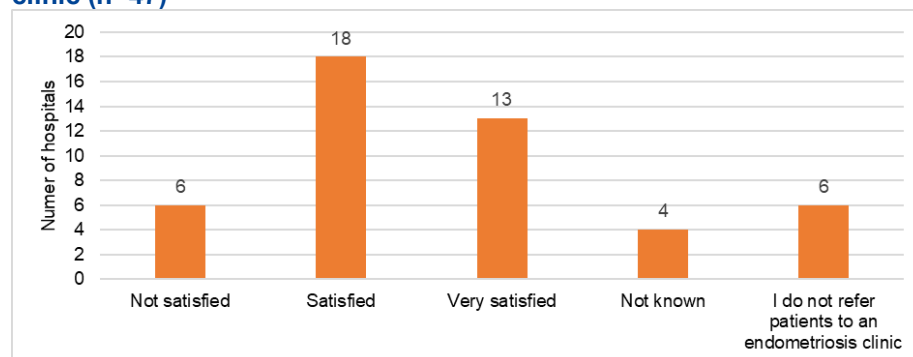


For the **surgical treatment of deep endometriosis**, eleven hospitals (23.4%) indicated that they always refer patients to a specialist within their own hospital (Figure 9, Table 39); an additional nine hospitals (19.1%) would refer patients either within the hospital or to an endometriosis clinic within (n=3) or outside (n=6) of their hospital network. Seven hospitals (14.9%) refer all surgery for deep endometriosis to an endometriosis clinic within their network; sixteen hospitals (34.0%) refer this type of surgery to an endometriosis clinic outside of the network, and the remaining four hospitals (8.5%) refer to an endometriosis clinic within or outside of the network.

Of note, no hospital without endometriosis clinic indicated that they would refer patients to a clinic abroad for diagnosis or treatment.

In general, hospitals are (very) satisfied with regards to the collaboration with the referral endometriosis clinic (n=31, 66.0%; Figure 10). Six hospitals indicated that they were not satisfied with the collaboration (12.8%). As main reasons for dissatisfaction, the respondents cited long waiting times, lack of feedback from the referral centre, and discontent with the clinical management of the patient.

Figure 10 – Satisfaction with the collaboration with the endometriosis clinic (n=47)



Key points:

- Overall, 77 Belgian hospitals responded to the questionnaire (response rate: 76.2%);
- Thirty hospitals reported having an endometriosis clinic; multidisciplinary team (MDT) meetings are organized in 23 out of them;
- A typical endometriosis team would be made up of at least a gynaecologist, an infertility specialist, an abdominal surgeon, a radiologist and a urologist, but, about two in three endometriosis clinics also have a pain specialist, a psychologist, a physiotherapist and/or a sexologist in the endometriosis team and one in two have someone in charge of coordination and continuity of care;
- Seventeen endometriosis clinics see ten to thirty new patients per month, but there are extremes with less than ten patients and more than fifty;
- Most endometriosis clinics (63.3%) perform six to twenty surgeries for endometriosis (excluding deep endometriosis) per month;
- The reported number of surgeries for deep endometriosis performed in the thirty endometriosis clinics ranges between zero and over fifty per year;
- Almost all hospitals (93.6%) without an endometriosis clinic report that they perform surgery for endometriosis; most of these hospitals (78.7%) perform between one and ten surgeries per month for endometriosis (excluding deep endometriosis);
- For the diagnosis of endometriosis, most hospitals without an endometriosis clinic rely on the within-hospital expertise available (59.6%);



- More than half of the hospitals without an endometriosis clinic (57.4%) refer patients for surgical treatment of deep endometriosis to an endometriosis clinic (within or outside the hospital network);
- In general, 66.0% of hospitals without an endometriosis clinic are (very) satisfied with regard to the collaboration with the referral endometriosis clinic.

5 WHAT CAN WE LEARN FROM OTHER COUNTRIES?

5.1 Introduction

As of today, the care for individuals with endometriosis has not been formally organised in dedicated centres in Belgium. So far, endometriosis care was based on bottom-up initiatives in some hospitals (see section 4.2). In this chapter we explore what we can learn from others in order to improve the organisation of endometriosis care in Belgium. First we list some key elements in endometriosis care. Then we further elaborate on what we can learn from Australia, Denmark, France, Germany, the Netherlands and the UK on the organisation of care, endometriosis registries, the recognition of endometriosis as a chronic condition and other rights for individuals with endometriosis, national action plans on endometriosis, training for health care professionals and information for patients and the public at large.

5.2 Methodology

For this chapter information was gathered from the literature searches that were performed in Medline and Cochrane on 3 and 7 August 2023, with the following themes: endometriosis, centres of expertise, multidisciplinary, health policy, quality indicators (see Appendix 5.1 for the search strategies and Table 40 for the inclusion and exclusion criteria). A dedicated search on the association between caseload and outcome in endometriosis care was run on 12 and 13 October 2023 (see Appendix 5.1 and Appendix 5.2 for the search strategies).

In addition, for six countries complementary information was gathered by searching for grey literature (e.g. policy reports, legislation) and by checking the reference lists of publications. Australia and France were selected as they both developed a national action plan for endometriosis.^{122, 124} Denmark, Germany, the Netherlands and the UK were also chosen since they all have organised endometriosis care to some extent, among others by the implementation of endometriosis expert centre.¹⁵⁸⁻¹⁶¹



For each selected country a template was completed by the authors of this report, which was sent out for review and completion to one or two expert(s) per country. These experts did not contribute to the drafting of this chapter, and can therefore not be held responsible for its content. The full country overviews can be found in Appendix 5.4 to Appendix 5.9.

5.3 Key elements in endometriosis care

When (re)organising the care for patients with endometriosis the following aspects are key:

1. Providing comprehensive, personalised care in the setting that best suits the care needs, symptoms and preferences

Many patients with endometriosis need individualized care for a long time.¹⁶² The priorities may change depending on the type and severity of symptoms, the impact of these symptoms, current or future fertility goals, age and lifestyle factors.^{159, 162} But, not all patients with endometriosis require several interventions and/or a large number of experts; some are treated effectively for the rest of their lives by e.g. a single laparoscopic surgical intervention.¹⁶² The way care is organised for patients with endometriosis should reflect this **diversity in care needs**.

In addition, the way care is organised should not only contribute to the reduction of morbidity, but also to increased knowledge and technical expertise among care providers, hence shortening the diagnostic delay, offering tailored care throughout the life course and improving patients' quality of life.

Given the high prevalence of endometriosis, it is impractical to manage all patients with endometriosis at the highest level of expertise (i.e. in a centre of expertise). Yet, it is important that they are **triaged to receive treatment in the setting that best suits their care needs, symptoms and preferences**.²

2. A multidisciplinary team approach¹⁶²

In view of the intricacy of symptoms, multiple organ systems that may be involved and clinical complexities involved in treating women with endometriosis and associated chronic pelvic pain (e.g. endometriosis does not respect the 'gynaecologic area', invading adjacent as well as distant organs, the limited efficacy of treatment options and relatively high risk of recurrence), the frequently occurring fertility treatment needs of patients, and the potential for significant negative impact on patients' functioning and quality of life, an evidence-based multidisciplinary care approach that leverages a patient-focused team of health care providers,^{159, 163-165} is essential 'to address the challenge of endometriosis'.¹⁶⁶ Multidisciplinary teamwork involves **coordinated efforts from various specialists**, with extensive expertise and experience in their respective disciplines applied to the management of a patient with endometriosis.⁶⁴

Studies indicated that multidisciplinary team (MDT) meetings ensure higher quality decision-making, reduced incidence of questionable practices, standardised patient care, and results in improved outcomes.¹⁶⁷⁻¹⁶⁹ A survey among endometriosis patients aiming to identify the best possible care, revealed that multidisciplinary care was a key component for the majority of respondents.¹⁷⁰

In addition, healthcare professionals also benefit from the multidisciplinary approach, for instance by learning from each other across disciplines through active discussions and case reviews, by experiencing how combined treatments can improve patient outcomes, and by providing support for more complex cases.¹⁷¹ Greater job satisfaction and psychological well-being have been reported as well.¹⁶⁷

Yet, while a multidisciplinary approach is considered good practice in the management of chronic conditions like endometriosis, assessments of the effectiveness of the established multidisciplinary endometriosis centres are few and far between,¹⁶⁵ and often based on single-centre studies,^{172, 173} that lack controls and robust data analysis.



3. Centres of expertise with dedicated specialists with a high caseload

Already in 1979, a relationship between higher surgical volume and reduced postoperative mortality was reported for a number of surgical procedures.¹⁷⁴ Since then, a vast amount of studies have come to the conclusion that **higher volume correlates to better outcomes and fewer complications, especially in complex and high-risk surgery**, like for instance complex cancer surgery.¹⁷⁵⁻¹⁷⁷ This conclusion has been confirmed in several systematic reviews.^{176, 178-182} Depending on procedure and outcome, a maturation in the surgical learning curve, i.e. a 'plateau phase', was observed at a caseload ranging from 25 to 750 procedures^{aaa, 182}

The volume-outcome relationship has been attributed to various factors, such as the multidisciplinary approach, better knowledge about proper indications, compliance to evidence-based care processes, level of specialization, learning-by-doing, postoperative care and several hospital level factors.¹⁸³⁻¹⁸⁵ Also the so-called "rescue phenomenon" has been associated with better outcomes, i.e. the ability to prevent minor postoperative events to develop to severe complications and eventually death.¹⁸⁶ Yet, the magnitude of the association varies greatly,¹⁷⁶ and no

conclusive set of explanatory factors has been identified to explain the causality of the volume-outcome relationship.¹⁸⁵

In endometriosis care, research on the association between (surgical) volume and outcomes is limited. A French retrospective study (with several methodological limitations^{bbb}) based on data of 1 135 cases of surgically managed colorectal endometriosis treated in fifty-six hospital facilities, concluded that volume of activity was independently^{ccc} correlated to the complication rate.¹⁸⁷ A retrospective observational study (with several methodological limitations^{ddd}) which included 937 women who underwent surgery for colorectal endometriosis in nineteen endometriosis expert centres^{eee} revealed a high variability of complications in low-volume centres, but also a significantly lower overall severe complication rate in the high-volume group compared to the medium-volume group (2.9% vs. 6.9%, $p=0.017$) without significant differences between other groups.¹⁹¹ Others observed a learning curve with regard to the assessment of deep pelvic endometriosis by means of ultrasound and magnetic resonance imaging.¹⁹² It was estimated that about 35 cases were needed in order to achieve competence, but a larger caseload was required to demonstrate the curve in full.¹⁹²

^{aaa} The authors of the systematic review identified several shortcomings in the primary studies (e.g. less than half adjusted outcomes for differences in case-mix, and less than a quarter considered clustering in the analyses, only 15 of 57 studies measured postoperative complications, only few studies measured patient satisfaction). They argue that this inadequate methodological rigor and consistency may (in part) explain the substantial variation identified between studies.¹⁸²

^{bbb} E.g. hospitals reported on a voluntary basis, so it is unclear how representative the data are for actual care; the authors 'suppose that some facilities with low volumes of activity did not participate in the study potentially contributing to underestimating the overall complication rate'; the analyses were focused on high-grade complications and did not take grade I-II complications into account.

^{ccc} In the multivariable analysis, the type of hospital (university vs. general vs. private), the use of protective defunctioning stoma (PDS) and the presence of a MDT were included as covariates.

^{ddd} E.g. hospitals reported on a voluntary basis, so it is unclear how representative the data are for actual care; the analyses were focused on high-grade complications and did not take grade I-II complications into account; no multivariable analyses were performed, hence other factors which have been shown to contribute to an increase of complication rates when performing colorectal surgery for deep endometriosis, such as height of anastomosis, comorbidities and vaginal opening,¹⁸⁸⁻¹⁹⁰ and other factors such as the presence of a MDT were not taken into account.

^{eee} The endometriosis expert centres were located in Germany, Switzerland, Czech Republic and Austria; eight centres performed less than forty procedures (group 1), six performed 40–59 (group 2) and five centres ≥ 60 (group 3) colorectal interventions from 1 January 2018 to 31 December 2019.



As it is essential that there is sufficient throughput to maintain surgical skills for the most complex cases of endometriosis,¹⁶³ it has been argued that certain subgroups of patients, like those with more advanced disease,¹⁶² deep endometriosis,³ rectovaginal endometriosis,¹⁶¹ and/or more refractory clinical problems, should receive care in a centre of expertise with high caseloads.¹⁶² However, as long as there is no universally accepted endometriosis classification,⁶ nor clear criteria to define expert centres,^{187, 193} it may be hard to reach consensus on referral guidelines.

4. Quality assurance through transparent recording and reporting of outcomes

While volume is a critical element, volume alone is not sufficient to predict the quality of healthcare: outcome-based evaluation is also needed.¹⁷⁹ In order to improve our understanding of surgical outcomes, the prospective collection of data and the standardisation of the reporting system have been proposed.^{194, 195} In doing so, care must be taken to ensure that the data registered are inclusive of the intended patient population so that selection bias in the outcome data can be avoided.¹⁶³

Several countries have taken action to improve the organisation of care for women with endometriosis. These initiatives, and especially those that may be a source of inspiration for Belgian policy makers, are elaborated in the following paragraphs.

5.4 Organisation of endometriosis care

5.4.1 Initiatives at the primary care level

In the UK, a **care pathway for endometriosis primarily aimed at the primary care level**, was developed (Figure 14).¹⁹⁶ It provides details on e.g. what should be covered during history taking and clinical examination when a patient presents possibly with endometriosis, which symptomatic treatment can be offered, but also criteria for referral to general gynaecology (e.g. for diagnostic services) and for referral to the specialist endometriosis clinic.¹⁹⁶

In Australia, twenty **endometriosis and pelvic pain GP clinics** are being rolled out across the country as of March 2023; they are established within the frame of the existing Primary Health Networks (Table 41).¹⁹⁷ They will provide multidisciplinary care with a focus on improving the timeliness of diagnosis and promoting early access to intervention, care, treatment options, and referral services for endometriosis and pelvic pain.¹⁹⁷ In addition, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) guideline^{fff} on the diagnosis and management of endometriosis includes consensus-based recommendations on when women with endometriosis should be referred from primary care to gynaecological specialist services.¹⁹⁸

^{fff} The RANZCOG guideline is based on the National Institute for Health and Care Excellence (NICE) guidance 'Endometriosis: diagnosis and management' (2017).²



5.4.2 Initiatives at the specialty care level

In Germany, **specialized endometriosis care** is since 2005 organised at **three levels**, which all have to fulfil a list of licensing standards in order to obtain (and maintain) certification:¹⁵⁹

- Level I - '*Endometriosepraxis*' (endometriosis practice): subspecialized gynaecological (private) practice, offering guideline-compliant diagnosis, therapy and patient counseling; minimal annual case load: 50 treated patients;
- Level II - '*Endometrioseklinik*' (endometriosis clinic): in addition to the care provided in the endometriosis practice, they also provide surgical treatment (usually hospital-based); minimal annual case load: 100 treated patients, among whom 50 surgical patients⁹⁹⁹;
- Level III - '*Endometriosezentrum*' (endometriosis centres): offering not only comprehensive endometriosis care, including highly specialized endometriosis surgery for deep endometriosis (plus interdisciplinary visceral and urological operations), but also special training courses for medical and surgical treatment of endometriosis; minimal annual case load: 100 surgical patients, among whom at least 10 cases with organ-transcending infiltrating spread (bladder, intestine, ureter). In addition, these centres must participate in scientific research.¹⁵⁹

Level I & II centres must have a formal collaboration with a Level III centre, a fertility centre, a psychological counselling practice, a pain clinic and physiotherapy department. Level II & III centres must report patient treatment data annually to the Endometriosis Research Foundation

('Stiftung Endometriose Forschung', SEF; cf. infra).¹⁵⁹ See Table 44 for all licensing standards (Appendix 5.7).

In France, a **two-level system** for endometriosis care has been developed, called level II and level III as level I represents primary care (Appendix 5.6):

- Level II offers medical management of endometriosis resistant to initial treatment, surgery for non-complex deep endometriosis (i.e. infiltrating the uterosacral ligaments or the posterior vaginal fornix which requires surgery that can be performed by a gynaecological surgeon only), assessment of pain and fertility, development of a personalised health plan, which may include adaptations for adolescents at school,²⁰⁰
- Level III offers medical management in case of complex situations, surgery in case of deep endometriosis with digestive or urinary tract involvement, extra-pelvic forms, multifocal or recurrent endometriosis, as well as situations requiring a surgical team with expertise in visceral, urological and gynaecological surgery.²⁰⁰

Also in Denmark, there is a two-level system: in addition to gynaecologists (specialised in endometriosis or not), there are two reference centres (Aarhus University Hospital and the Rigshospitalet in Copenhagen) which are authorized to diagnose and treat patients with advanced endometriosis (Table 42, Appendix 5.5).^{201, 202}

The organisation of endometriosis care in the Netherlands fits within the health system's wide NENI norms^{hhh, 203} In order to improve the quality of care offered to patients affected by endometriosis, they go all out for **regional collaboration between level-1 centres**, which offer basic endometriosis care, **and level-2 centres**, which offer complex

⁹⁹⁹ Surgical patients are defined as patients younger than 50 years. Each patient can only be assigned to one surgeon. Dedicated surgeons must carry out or assist in at least 30 surgeries per year and at least 80% of elective surgeries are carried out by dedicated surgeons. Hysterectomies also count if the indication is dysmenorrhea and adenomyosis as proven by histology. Histology must be available for all cases; for laparoscopic surgery, a false-negative rate up to 20% is accepted for histology.¹⁹⁹

^{hhh} The Note Requirements Standards for Institutions, also known as the NENI norms ('Nota Eisen Normen voor Instellingen', NENI), sets out requirements and standards to which health care centres are held when they want to provide low-complex (category 1), complex (category 2) and high-complex care (category 3). The requirements (e.g. on the knowledge and skills of the health care providers who (wish to) offer/provide certain types of care) and (volume) standards are described from the point of view of safety of care.²⁰³



endometriosis care.²⁰⁴ Licensing standards for level-1 (considered category 2, i.e. offering complex care, according to the NENI norms) and level-2 centres (considered category 3, i.e. offering high-complex care, according to the NENI norms) are based on **clinical, professional, organizational, educational and research aspects** (see Table 45, Appendix 5.8). For instance, in level-1 centres, at least one of the gynaecologists who is involved in endometriosis care, has to demonstrate attending continuing education in the field of endometriosis. Level-2 centres have to perform at least fifty surgical interventions for endometriosis per year, of which at least twenty for deep endometriosis per centre per year. Importantly, the gynaecologist performing the surgery for deep endometriosis has completed a learning curve of at least fifty procedures for deep endometriosis.²⁰⁴ The Dutch Society for Obstetrics and Gynaecology ('Nederlandse Vereniging voor Obstetrie en Gynaecologie, NVOG') has not only formulated the minimal requirements for level-1 and level-2 centres, but is also responsible for the certification of both. Every five years, **adherence to the licensing standards** is audited by a quality committee of the NVOG.²⁰⁴

While the NICE guideline for endometriosis recommends multidisciplinary care centres in second and third line,² this has not been structurally implemented yet in the second line in the UK (Table 46).⁷¹ Accreditation for endometriosis reference centres (i.e. third line care) was started in 2008; multidisciplinary care is among the requirements for accreditation.²⁰⁵ Centres who wish to be recognised, must register first as '**Provisional endometriosis centre**', during which time they can work towards the requirements for accreditation. Once they are audited by the British Society

for Gynaecological Endoscopy (BSGE; each year in December), they can be accredited.¹⁶¹ Accreditation is **reviewed annually**. Importantly, as it is considered essential that there is '**sufficient workload throughput to maintain surgical skills for the most complex cases**', every gynaecological surgeon employed in the endometriosis reference centre, has to perform annually **at least twelve cases of rectovaginal endometriosis**, which require dissection of the pararectal space. In addition, all cases of rectovaginal endometriosis must be entered into a **database**, and must be followed up for two years post-surgery (cf. section 5.5).²⁰⁶ Another requirement for the endometriosis reference centres, is a **dedicated endometriosis specialist nurse** (cf. section 5.4.2.1 and Box 8), who can carry out primary patient contact to triage referrals, collect patient symptom questionnaires and perform selected patient follow up appointments.

5.4.2.1 Endometriosis expert centre - composition of the team

In all selected countries, a multidisciplinary team of experts is involved in the care at the (highest level of) endometriosis expert centres (Table 1). Most often, the core members are specialists in gynaecology, abdominal/colorectal surgery, urology, imaging and pain therapy, and a gynaecology specialist nurse. In a recent systematic review on multidisciplinary care in endometriosis, not only gynaecologists, but also physiotherapists and psychologists were reported most commonly in existing multidisciplinary care models.¹⁶⁵


Table 11 – Composition of the multidisciplinary teams in endometriosis expert centres

Specialism	Denmark [§]	France ²⁰⁰	Germany ^{*159}	The Netherlands ^{#204}	UK ¹⁶¹
Gynaecology	Y	Y [§]	Y	Y	Y
Visceral/digestive/colorectal/abdominal surgery	T	Y	Y	Y	T
Thoracic surgery	T				
Urology	T	Y	Y	Y	T
Imaging/radiology	T	Y [§]	Y	Y	Y
Pathological anatomy			Y		
Pain therapy	T	Y	Y	T	T
Fertility	T	Y	Y		
Physiotherapy/rehabilitation			Y		
Nutritional counselling			Y		
Clinical expert in endoscopy	Y				
Gastrointestinal diseases	T			T	
Pelvic physiotherapy				T	
Psychology				T	
Dedicated endometriosis nurse	Y			T	Y
Supportive care (e.g. social worker)					

Y: present during multidisciplinary team meeting/core interdisciplinary members; T: tentatively present during multidisciplinary team meeting and/or regularly scheduled attenders; §: data for Denmark provided by reviewer; §: in France a distinction is made between medical gynaecologists and surgeon-gynaecologists, and radiologists are specialised in endometriosis imaging; ; *: for Germany the team of the level III endometriosis centres is considered; #: for the Netherlands the team of the level-2 endometriosis expert centres is considered; in Australia there are only self-proclaimed tertiary expertise centres, hence Australia is not included in this table.



Continuity of care is pivotal for all persistent and/or chronic diseases.¹⁶⁶ Patients with long-lasting complaints, should have a **continued point of reference**, who coordinates, individualizes the long-term treatment plan,¹⁶⁶ and refers when indicated.

In the UK, the clinical nurse specialist in endometriosis takes on this task; (s)he is a key post within the endometriosis teams.¹⁶¹ Even more, since 2014, accreditation of endometriosis reference centres is dependent on having a clinical nurse specialist in endometriosis as member of the multidisciplinary team. This role has been further recognised by the NICE guidelines (2017).² The requirements and main responsibilities as outlined by the Royal college of Nursingⁱⁱⁱ, are listed in Box 8.¹⁶¹

Box 8 – Clinical nurse specialist (CNS) in endometriosis – Main outlines

- **Requirements:** To become an endometriosis CNS, nurses will have had:
 - extensive experience working within a gynaecology or women's health setting;
 - will have been educated to masters level and display masters level thinking and decision making;
 - have insight into the condition and all of the areas of management, including the wider social political dimensions of this condition.
- **Responsibilities:** The responsibilities of the endometriosis CNS within a specialist centre would encompass:
 - elective outpatient follow-up at three months by a consultant and six months by a specialist nurse, with woman-related outcome measures (PROMs) including quality of life post-surgery assessments at six, 12 and 24 months;

- working in a multidisciplinary team that includes a named colorectal surgeon and nurse specialist in endometriosis;
- on their initial visit to the centre, women will be seen by the endometriosis specialist nurse and a full review of symptoms including completion of a quality of life questionnaire will be undertaken:
 - where investigations are incomplete or additional ones are needed these can be performed or booked;
 - ideally the nurse should be able to organise or perform a pelvic and renal ultrasound if these are not supplied with the referral;
 - detailed literature about all treatments including surgical treatment will be given to the woman and likely next steps discussed;
 - if a diagnostic laparoscopy is required this will be organised directly by the nurse who will discuss each case with the doctor and multidisciplinary team;
- careful scrutiny of the referrals by the endometriosis specialist nurse will optimise this arrangement;
- women will have contact details of the endometriosis specialist nurse and make contact if problems develop.

Source: Royal college of Nursing, 2021¹⁶¹

ⁱⁱⁱ According to a factsheet issued by the Royal College of Nursing (RCN), there is a consensus in the UK that specialist nurses should also have completed

a 1 year full-time degree level programme involving 50% theory and 50% practice. It is not clear whether this is enforced to be able to claim the title of CNS.²⁰⁷



5.4.2.2 Endometriosis expert centre - referral criteria

In Australia there are only self-proclaimed tertiary expertise centres, hence there are no clear referral criteria. In France, patients who need the care offered in level III centres can only access these centres after formal referral agreed during an MTD.²⁰⁰

Yet, while the other four countries have recognised reference centres, no clearly defined referral criteria were identified.

5.4.2.3 Endometriosis expert centre - licensing standards

The licensing standards for the endometriosis reference centres in Germany, the Netherlands and the UK are summarized in Table 12. For the Danish endometriosis reference centres no licensing standards were identified, in addition to the formal guidelines from the Danish Health and Medicines Authority (DHMA) with regard to the centralised treatment of advanced disease in 2001.²⁰⁸ In France, endometriosis reference centres must meet the specifications of the region in which they are located,¹²² and in Australia there are only self-proclaimed tertiary expertise centres, hence they have no formal licensing standards.

Table 12 – Endometriosis expert centres – licensing standards

Licensing standards	Germany* ^{159, 199, 209}	The Netherlands ^{#204, 210, 211}	UK ^{161, 212}
Coordination	The head of the centre or a designated surgeon must have an additional qualification in the field of endometriosis (e.g. qualification course of AGEM).		
Multidisciplinary approach	Monthly interdisciplinary endometriosis conferences OR documented interdisciplinary therapy plans At least 10 documented interdisciplinary therapy plans per year	Multidisciplinary meeting to discuss possible surgical indication	
Team	Cf. Table 1	Cf. Table 1	Cf. Table 1
Continuity of care - case manager			An endometriosis specialist nurse is required, who carries out primary patient contacts and triage (Box 8).
Training & expertise of the team	At least one further training course on the topic of endometriosis for doctors and medical staff per year Head of the centre (required) and the other gynaecologists working in the centre (highly recommended) should have demonstrable expertise in the field of minimally invasive surgery OR have the specialty title of	The gynaecologist who performs the surgical interventions for deep endometriosis, has at least experience from 50 surgeries for deep endometriosis.	



Licensing standards	Germany* ^{159, 199, 209}	The Netherlands ^{#204, 210, 211}	UK ^{161, 212}
	gynaecological oncology or gynaecological endocrinology		
Volume (annual)	- At least 100 surgical patients⁹⁹⁹, of which at least 10 cases with organ-transcending infiltrating spread (bladder, intestine, ureter) - At least 10 documented interdisciplinary therapy plans	- At least 50 new patients per year - At least 50 surgeries for endometriosis per year, of which at least 20 for deep endometriosis	- At least 12 surgeries for rectovaginal endometriosis (requiring dissection of the pararectal space) per surgeon per year
Registration & reporting	Submission of a structured annual report, which has to be submitted to EuroEndoCert (cf. infra; these reports are not publicly available)	- Registration of data (format provided by the NVOG working group endometriosis): number of new patients, number of surgeries, complications, patient satisfaction - An annual survey is sent out by the patient association ('Endometriose stichting') to all (candidate) level-1 & level-2 endometriosis centres, collecting information on the organisation of care, the level expertise and the case load. The results are published on the website of the patient association and a summary report is published on the website of the NVOG.	- All rectovaginal endometriosis procedures must be recorded in the BSGE database and followed up for 2 years post-surgery - Submission of an exemplar video of surgery for laparoscopic excision of severe rectovaginal endometriosis that required dissection of the pararectal space. - The annual number of surgeries per accredited centre can be found on the BSGE website.
Collaboration with fertility centre		All fertility treatments must be offered in the level-2 clinic; preferably, the fertility specialist and the gynaecologist both work at the level-2 clinic.	
Collaboration with pain centre			A support network, with an urologist and pain management specialist providing active support, is required.
Regional collaboration	The endometriosis centre functions as a (supra-regional) referral centre for collaborating endometriosis clinics and practices. This collaboration entails for example the invitation of the clinics to monthly interdisciplinary endometriosis meetings in the endometriosis centre and the organization of observerships for specialists from the clinics	The level-2 centre organises the collaboration between level-1 and level-2 centres in the region.	



Licensing standards	Germany ^{*159, 199, 209}	The Netherlands ^{#204, 210, 211}	UK ^{161, 212}
Research	In the last 3 years, - The publication of at least 1 paper on primary research, listed in Web of Science, with first or senior author from the centre, or - Participation in a clinical trial (multicentre study with ethical clearance) with inclusion of at least one patient, or - Participation in ongoing third-party funded project and - At least 1 assignment per year as speaker at a conference (abstract, lecture, poster), or - The publication of a review paper, or - The publication of a case report, or - The publication of a book chapter	The level-2 centre has to show evidence of participation in scientific research (in collaboration with other centres or own initiative)	
Collaboration with patient association	Yes		
Length of recognition & audit	EuroEndoCert, a physician-led service provider, provides certification for endometriosis clinics on behalf of the SEF; The certification lasts for 3 years, and recertification does not occur automatically; The names of certified centres are published on the EuroEndoCert website and EEL.	Adherence to licensing standards is audited by a quality committee of the NVOG every 5 years.	Adherence to licensing standards is audited yearly in December by BSGE for accreditation the following year.

AGEM: Working Group for Endometriosis in the German Society for Gynaecology and Obstetrics ('Arbeitsgemeinschaft für Endometriose in der Deutschen Gesellschaft für Gynäkologie und Geburtshilfe e.V. '); SEF: Endometriosis Research Foundation ('Stiftung Endometriose Forschung'); EEL: European Endometriosis League; NVOG: Dutch Society for Obstetrics and Gynaecology ('Nederlandse Vereniging voor Obstetrie en Gynaecologie'); BSGE: British society for Gynaecological Endoscopy; *: for Germany the licensing standards of the level III endometriosis centres are considered; #: for the Netherlands the licensing standards of the level-2 endometriosis expert centres are considered.



5.5 Endometriosis registry

Two national endometriosis registries were identified: the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry and the British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres Database (Table 13). The former was introduced just recently with the aim 'to investigate the long-term patient outcomes, impact, prognosis, causes and treatment of endometriosis and its related symptoms and conditions'.²¹³ Adults with suspected or confirmed endometriosis, who speak English, are invited to complete online surveys, and if they consent, additional information is added by their treating physician and collected from administrative databases.²¹⁴

The BSGE database rests on the registration of surgical cases of severe rectovaginal endometriosis (i.e. surgery that required dissection of the pararectal space); the registration is mandatory for BSGE endometriosis centres in order to be certified.¹⁶¹ **Outcome data on pain, quality of life and a standard set of possible complications** are collected.¹⁶³ Over the early years these have been modified to ensure they captured the most appropriate quality measures for patients with endometriosis. These are now standardised, so benchmarking of outcome data between BSGE accredited endometriosis centres is possible.¹⁶³

The annual number of surgeries for severe rectovaginal endometriosis per certified centre is provided on the BSGE website (<https://www.bsge.org.uk/data-for-bsge-accredited-endometriosis-centres/>).¹⁶¹ So far, one multi-centre paper describing the results on 5 162 women who underwent surgery for deep rectovaginal endometriosis in one of the BSGE certified endometriosis centres between 1 January 2009 and 30 June 2016, was published.²¹⁵

In Germany, France and the Netherlands, there is no endometriosis registry. Yet, in the Netherlands structural information is gathered by the patient association ('Endometriose Stichting') with an annual online survey completed by hospitals offering endometriosis care (Table 45); participation of the hospitals is on a voluntary basis.²¹⁰ The collected information is published on the association's website (<https://www.endometriose.nl/index.php?page=728&sid=1>).


Table 13 – Endometriosis registries in Australia & the UK

Characteristics	The Australian National Endometriosis Clinical and Scientific Trials (NECTS) Registry ^{213, 214}	The British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres Database ^{161, 212, 215}
Country	Australia	United Kingdom
Inception	2022	2007
Coverage	National	National, restricted to those surgically treated for severe rectovaginal endometriosis in certified centres
Funding	National Australian Government's Medical Research Future Fund (MRFF)	British Society for Gynaecological Endoscopy (BSGE)
Population	Patients > 18 years, with suspected or confirmed endometriosis, who speak English	Surgical cases of severe rectovaginal endometriosis (i.e. surgery that required dissection of the pararectal space)
Data provision	Surveys completed by patients and (upon patient consent) MD, linked to administrative database	Data provided by certified centres (one of the conditions for certification; cf. Table 12)
Data	Patient: - Demographics - Clinical presentation and medical history - QoL (overall (EQ-5D-5L) and endometriosis (EHP-30)) MD: - Diagnosis & imaging (US/MRI) - Medical & surgical management - Histopathology - Environmental and lifestyle risk factors	- Demographics Patient: - Clinical symptoms (e.g. pain, bowel function) and medical history - QoL (overall: EQ-5D-3L & EuroQol Visual Analogue Score) MD: - Previous endometriosis surgery - Surgical management, incl. complications
Frequency of registration	BL, 6 & 12 months, annual	BL, 6, 12 & 24 months post-surgery
Aim(s)	To provide large-scale population-based data at a national level on endometriosis. To understand the causes of endometriosis and improve care and quality of life for individuals living with endometriosis (including adenomyosis).	Quality assessment of the certified endometriosis centres
Objectives	- To assess the overall QoL of endometriosis patients using validated PROMs tools (EQ-5D-5L, EHP-30);	



Characteristics	The Australian National Endometriosis Clinical and Scientific Trials (NECTS) Registry ^{213, 214}	The British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres Database ^{161, 212, 215}
	- To detect the incidence of other conditions, including adenomyosis, fibroids and symptoms related to endometriosis; - To estimate the incidence of diagnosis of endometriosis via imaging methods (including ultrasound and/or MRI); - To estimate the proportion of participants being managed expectantly vs. medically vs. surgically vs. allied health and/or complementary therapies; - To estimate the incidence of adverse events.	
Results	Not (yet) [#]	Analysis of the data on 5 162 women who underwent surgery for deep rectovaginal endometriosis in one of the BSGE certified endometriosis centres between 1 January 2009 and 30 June 2016, provided overall good results, with e.g. significant reductions in endometriosis-related pain at 6 months post-surgery, which were sustained at 2 years. ²¹⁵ Also for other outcome variables (e.g. QoL, voiding difficulty, bowel frequency, urgency, incomplete emptying, constipation, passing blood) the results were favourable. Yet, there was no control group (e.g. patients treated outside BSGE certified endometriosis centres). ²¹⁵
Public reporting	Not (yet)	The annual number of surgeries per certified centre is provided on the BSGE website.

QoL: quality of life; PROMS: patient-reported outcomes measures; BL: baseline; EQ-5D-5L: 5-dimension health-related quality of life instrument developed by the EuroQol Group; EHP-30: 30-item Endometriosis Health Profile questionnaire; SF-36: 36-Item Short Form Survey; #: besides a brief overview of clinical presentation measurements of the first 890 participants.²¹⁶



5.6 Recognition of endometriosis as a chronic condition

In Australia there is no standard definition nor list of eligible chronic conditions, but GPs can propose a Chronic Disease Management Plan and Team Care Arrangements when a patient experiences symptoms (e.g. chronic pelvic pain) for at least six months (see Table 41). Citizens eligible for Team Care Arrangements may receive up to five subsidized allied health sessions per calendar year (e.g., mental health services, occupational therapy, physiotherapy, and psychology).²¹⁷ Despite the availability of a Chronic Disease Management Plan, a cross-sectional survey among 620 Australian women indicated that only 15% of endometriosis patients indicated having such a CDMP.⁹

In France, endometriosis is not included in the list of 30 long-term conditions ('Affection Longue Durée', also known as ALD-30), however, citizens with the 'most severe types of endometriosis which are affecting the QoL', may fall within the scope of an 'off-list', also known as ALD 31. The ALD31 list contains serious conditions (not included in the ALD 30 list) that progress over a foreseeable period of more than six months and for which the treatment is particularly costly (Table 14).²¹⁸

In none of the other selected countries endometriosis is (automatically) recognised as a chronic condition.

Table 14 – Endometriosis – Recognition as a chronic condition

Characteristics	France ^{219, 220}
Inception	2022
Statute	Endometriosis is not included in the list of 30 long-term conditions (Affection Longue Durée (ALD) 30) ⁱⁱⁱ . Yet, certain types of endometriosis may, in certain cases, fall within the scope of an 'off-list', also known as ALD 31, i.e. a serious condition (not included in the list for ALD 30) that progresses over a foreseeable period of more than six months and which treatment is particularly costly.
Criteria	In order for examinations and treatments to be eligible for ALD 31, the patient's treatment must comprise: - the patient's treatment must comprise drug treatment; and - 2 of the following 4 criteria must be present: • Future hospitalisation • Repeated technical medical procedures • Repeated clinical biology procedures • Frequent and regular paramedical care
Procedure	The treating doctor must submit a request to the health insurance, together with a care protocol. The health insurance decides whether or not to grant ALD 31 status on a case-by-case basis.
Which types of endometriosis	The 'forms of endometriosis affecting the QoL'
Benefits for the patient	Co-payments are waived for procedures covered by the health insurance at the agreed rates; not all medical costs are covered (e.g. supplements, alternative medicine and lumpsums). ²¹⁸

ⁱⁱⁱ There are two types of 'Affection Longue Durée' (ALD) 30: If patients suffer from a serious illness that lasts for more than six months and requires costly treatment, the healthcare costs associated with the illness are covered up to the maximum reimbursable amount by the health insurance. In other words, patients are exempt from co-payment. However, there are still certain costs (e.g. supplements, the €1 lumpsum, the lumpsum for hospital admission) that

need to be paid by the patient.²¹⁸ In case of a serious illness that does not require costly treatment, the second type of ALD 30 may apply. In that case, patients are not exempt from co-payment (i.e. the health insurance reimburses treatment related to the disease at the usual rates), but patients can take sick leave for more than six months and (subject to certain conditions) transport costs are covered.²¹⁸



5.7 Other acquired rights for patients with endometriosis

In Denmark, patients with confirmed endometriosis may apply for a 'single supplement' for **contraceptives and hormonal treatments**, upon the condition that the physician approves that they are used for medical purposes, i.e. to treat endometriosis.²²¹ In case patients can't tolerate a certain type of birth control pill, they can apply for an 'increased supplement'.^{kkk, 222}

5.8 National action plan for endometriosis

Australia and France have both come up with a national action plan for endometriosis.^{122, 124} The Australian five-year national action plan for endometriosis was launched in 2018, from a partnership between government, endometriosis experts and advocacy groups (Table 41).¹²⁴ The three main axes are: awareness and education for the public at large (e.g. school menstrual education programs) as well as the healthcare sector, clinical management and care (e.g. the development of care pathways, from first consultation through to post-operative care), and research. The French national action plan for endometriosis (2022-2025) does not only involve the Ministry of Health, but also the Ministry of Gender Equality, Diversity and Equal Opportunities, the Ministry of Education, Youth and Sport and the Ministry of Labour, Employment and Social Inclusion (Table 43).¹²² The national plan pays attention to specific concerns such as economic vulnerability and disability. The plan is set up around five domains: informing, communicating and raising awareness; strengthening training for professionals; better detecting the disease; guaranteeing comprehensive, personalised care throughout the country; promoting research and innovation.¹²²

kkk In Denmark, when you opt for a more expensive version of a drug, you have to pay the difference between the cheapest and more expensive medication

5.9 Training on endometriosis for health care professionals

Since March 2020, the European Endometriosis League (EEL) is running a masterclass, i.e. a certified education and training educational program in diagnosis and therapy of endometriosis for gynaecologists, following a standardized curriculum.²²³

In addition, in the selected countries various initiatives have been taken to enhance the training of health care professionals on endometriosis; they can be found in Table 41 to Table 46. Here, we provide some examples of initiatives that may be worth considering for the Belgian context:

5.9.1 Initiatives for health care professionals of the primary care level

- The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) **Endometriosis eLearning Module**, a free self-directed online e-learning module;²²⁴
- **Endofonen** offers Danish health care workers who need advice, or extra information about endometriosis the possibility to contact specialist(s) at one of the endometriosis reference centre by telephone;^{225, 226}
- The French health authority ('Haute Autorité de santé', HAS) published a summary of the HAS guideline for endometriosis dedicated to general practitioners; it includes a description of symptoms and care pathways, as well as recommendations for clinical assessment, quality of life assessment, communication with patients and treatment;²²⁷
- The Royal College of General Practitioners (RCGP, UK) developed an online Menstrual Wellbeing Toolkit for GPs, which contains, among others, 'Top tips for managing endometriosis in primary care'.²²⁸

out of your pocket. However, if you suffer from allergies or other side effects when taking the cheapest drug, you can apply for the full reimbursement of the more expensive medicine, which is called an 'increased supplement'.



5.9.2 *Initiatives for health care professionals of the specialty care level*

- The Danish three years training program for gynaecologists in endometriosis comprises clinical work at a reference centre, scientific meetings, courses and research, as well as three months training abroad;
- The German Endometriosis Research Foundation ('Stiftung Endometriose Forschung', SEF) and the Working Group for Endometriosis of the German Society for Gynaecology and Obstetrics ('Arbeitsgemeinschaft für Endometriose in der Deutschen Gesellschaft für Gynäkologie und Geburtshilfe e.V.') have been organizing seminars for qualification of gynaecologists as endometriosis experts.²²⁹ These courses are part of the licensing standards for endometriosis centres (cf. section 5.4.2);
- The Level-2 centres in the Netherlands provide continued education to gynaecologists focused on endometriosis and fertility;²⁰³
- The Royal College of Obstetricians & Gynaecologists offers an advanced training module in obstetrics & gynaecology, which covers, among others, the laparoscopic excision of superficial and deep infiltrating endometriosis.²³⁰

5.10 Information for patients & the general public

In the selected countries several initiatives were identified to inform patients and increase awareness on endometriosis for the general public (Table 41-Table 46). Again, we provide a short list of examples that may be inspiring for the Belgian context:

- Based on the NICE guideline on endometriosis (published September 2017) a decision aid for women with endometriosis symptoms to help them make informed decisions about hormone treatment with hormonal contraceptives to try to improve their symptoms was developed.²³¹ It is accompanied by a user guide for healthcare professionals;²³²
- The RANZCOG Raising Awareness Tool for Endometriosis (RATE; <https://www.cognitoforms.com/f/zYpsFXGgJU6rZe8W0IVotA?id=131>), an online tool for primary health care professionals and their patients to help identify endometriosis;²³³
- The Periods, Pain and Endometriosis (PPEP Talk®) Program (<https://www.pelvicpain.org.au/ppep-talk-schools-program/>), a pain education program for students in Australia which aids in informing and educating students to recognise and identify whether their pain is normal, how all the different symptoms fit together, simple ways to reduce their pain, and how to look for further help if pain is severe;²³⁴
- EndoZone (<https://www.endozone.com.au/>), an Australian digital health platform co-created by researchers, clinicians, and the endometriosis community with evidence-based information for the general public, persons affected by endometriosis, and health care professionals.



6 GUIDELINES & QUALITY INDICATORS ON ENDOMETRIOSIS

In the Resolution on Endometriosis, adopted in the federal Parliament in April 2023 (see section 1.2), KCE was asked (among other things) to develop a Belgian guideline for the diagnosis and treatment of endometriosis, and to develop in a second phase quality indicators to assess the quality of care offered in Belgium.³⁹ In this section we explain why KCE opted not to develop a Belgian guideline on endometriosis and which obstacles can be expected when calculating process indicators based on routinely available databases. The assessment, selection and operationalisation of quality indicators for the Belgian setting was considered out of scope for this report.

6.1 Guidelines on endometriosis

In the last decade, several guidelines have been published on the diagnosis and treatment of endometriosis (Table 47, Appendix 6.1). The most recent guideline was published in 2022 by the **European Society of Human Reproduction and Embryology (ESHRE)** and had a search range from inception to December 2020.³³ Several experts working in Belgian hospitals participated in the development of the ESHRE guideline. Two authors of the present report (FD & RL) appraised independently the methodological quality of the ESHRE 2022 guideline according to the Appraisal of Guidelines for Research and Evaluation instrument (AGREE II),^{235, 236} and concluded that the overall quality was good (Table 48).

In the ESHRE guideline it is highlighted that ‘there still remain **many unanswered questions** for which no, or only poor quality or little data are available’.³³ The **scant evidence in the field of endometriosis diagnosis**

and treatment is reflected in the level of evidence^{III} of the 109 recommendations: none are based on high level of evidence, only eight on moderate level of evidence, while thirty were classified as ‘good practice points’ (GPP), i.e. mainly based on the expertise and opinion of the Guideline Development Group.

In Annex 5 of the ESHRE guideline, the authors provide **flowcharts for clinical practice** on the diagnosis of endometriosis, the treatment of endometriosis-related pain, the treatment of endometriosis-related infertility and on endometriosis and pregnancy. Based on the clinical practice guideline, ESHRE developed an **information booklet for patients**, which is (free of charge) available in English, Dutch and German on the ESHRE website (<https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline/Patient-version>).

Recently, the Flemish Society for Obstetrics and Gynaecology (VVOG) started the adaption of the ESHRE 2022 guideline to the Belgian/Flemish context according to the ADAPTE methodology^{mmm}.²³⁸ The section on ‘diagnosis’ was finalised in June 2023 (publication expected in spring 2024) and the section on ‘treatment’ is in development (publication expected in June 2024)ⁿⁿⁿ. To the best of our knowledge, no such initiatives have been launched by the French-speaking professional or scientific associations in Belgium.

^{III} The quality of evidence was classified in four categories according to GRADE (high, moderate, low, and very low).²³⁷ The quality of evidence reflects the extent to which a Guideline Development Group’s confidence in an estimate of the effect is adequate to support a particular recommendation.²³⁷

^{mmm} The ADAPTE methodology provides a systematic approach to adapting guidelines produced in one setting for use in a different cultural and/or organizational setting.²³⁸ More information is provided here: <https://g-i-n.net/>.
ⁿⁿⁿ Both sections will be publicly available and free of charge via the official website of the VVOG (www.vvog.be), but also via www.gunaikeia.be.



6.2 From quality goals to quality measurements^{ooo}

6.2.1 Introduction

In order to achieve improvements of the quality of care that is offered, setting standards through the development of guidelines and clinical pathways is not sufficient.²⁴⁰ A survey on the awareness of the NICE guideline on Endometriosis and the NICE quality standards (QS172) on endometriosis amongst healthcare professionals illustrates this.²⁴¹ While staff from endometriosis specialist centres were all aware of the NICE guideline and had full knowledge of it, this was not the case among non-specialist gynaecologists. They were generally aware of the guideline, but in some cases did not feel fully up to date or knowledgeable about its content.²⁴¹ An assessment of the impact of four ESHRE guidelines, among which the guideline on the management of endometriosis, came to comparable conclusions.²⁴² Overall, about 90% of the clinician-respondents (N=260) knew and downloaded the guideline on endometriosis, while 72% reported to use the guideline in their routine practice. About one in two of the clinician-respondents reported that the ESHRE guideline resulted in changes in their practice, with one in three who made changes perceiving that their patients benefitted from it. Only 12% referred patients to the patient-friendly version of the ESHRE guideline on endometriosis.²⁴²

Setting standards by itself does not lead to change. For that purpose, standards need to be **monitored** (e.g. through audit and feedback, accreditation, certification) and necessary **actions** must be taken to implement change (e.g. pay for quality, public reporting).²⁴⁰ Based on the recommendations adopted in clinical practice guidelines, quality indicators can be developed to aid the monitoring of care. In the context of improving endometriosis care in Belgium, quality indicators can for instance be used to document the quality of care, to make comparisons between hospitals

(i.e. benchmarking), to support regulation and recognition, to support quality improvement and to support patient choice (e.g. choosing a hospital).

Box 9 – Donabedian's classification of quality indicators

Quality indicators have been classified as:

- **Structure indicators**, which describe the type and amount of resources ('input') used by a health system or organization to provide healthcare. They relate to material resources (e.g. facilities, capital, equipment, drugs), intellectual resources (medical knowledge, information systems) and human resources. The assessment of structure is a judgement on whether care is being provided under conditions that either promote or hamper the provision of good care.
- **Process indicators**, which assess what health care providers did for the patient and (ideally) how well it was done. Processes can be subdivided into patient-related processes (e.g. prescription patterns, intervention rates, referral rates) and organizational aspects (e.g. supply with drugs, management of waiting lists, payment of healthcare staff, collection of funds). Clinical practice guidelines focus on the quality of care processes.²⁴⁰
- **Outcome indicators**, which (attempt to) describe the effects of care processes on the health status and wellbeing of patients (and populations). Donabedian distinguishes final outcomes, such as mortality, morbidity, disability or quality of life, from intermediate outcomes (e.g. blood pressure, body weight, personal well-being, functional ability, coping ability and improved knowledge).²⁴³

Sources: Donabedian, 1966 & 1988,^{243, 244} Mainz, 2003²⁴⁵

^{ooo} The authors do not pretend to provide in this section an exhaustive overview of the methodology of developing quality indicators. This section is only intended to give some methodological background to understand the various challenges in developing quality indicators for the diagnosis and treatment of

endometriosis, described in section 1.3. For more in-depth background information, the reader is referred to 'Measuring healthcare quality' by Quentin et al., 2019.²³⁹



Based on the concept of 'input – process - output' applied in industrial manufacturing, Donabedian proposed the triad of **structure, process and outcome** for the description and evaluation of the quality of healthcare.²⁴⁴ Translating Donabedian's position that 'good structure increases the likelihood of good processes, and good processes increase the likelihood of good outcome',²⁴³ to endometriosis care: the availability of the right mix of qualified professionals at a hospital increases the likelihood that infertility treatment or chronic pelvic pain management will be performed following current professional standards, and this in turn increases the likelihood of desirable outcomes.

It is important to note, however, that elements of the care process do not **signify quality** until their **relationship to desirable outcomes** has been proven.^{244, 246} Only after it has been demonstrated that certain procedures, used in specific situations and/or for certain (subgroups of) patients, are clearly associated with desirable outcomes, the presence or absence of these procedures, in such situations and/or for such patients, can be accepted as evidence of good or bad quality.^{243, 244, 247}

In essence, quality indicators are '**quantitative measures that provide information about the effectiveness, safety and/or patient-centredness of care**'.²³⁹ Therefore, quality indicators should provide:²³⁹

1. **A quality goal**, i.e. a clear statement about the intended goal or objective; for example, when performing surgery in women with ovarian endometrioma, clinicians should perform cystectomy instead of drainage and coagulation, as cystectomy reduces recurrence of endometrioma and endometriosis-associated pain;³³
2. **A measurement concept**, i.e. a specified method for data collection and calculation of the indicator; for example, the proportion of women with ovarian endometrioma, in whom cystectomy, and not drainage and coagulation is performed during surgery; and
3. **An appraisal concept**, i.e. a description of how a measure is expected to be used to judge quality; for example, if in 90% of women with ovarian endometrioma, cystectomy is performed during surgery, and not drainage and coagulation, this is considered to be good quality.

Importantly, measures without an appraisal concept (i.e. a defined threshold) are unable to indicate whether measured values denote good or bad quality of care.²³⁹

6.2.2 Data for quality measurement

Quality measurement requires data. A principal element of any quantitative assessment is **data quality**. Indeed, the reliability of quality measures relates to the quality of the data on which they are based and the robustness of the methods used.²³⁹ It has to be assessed whether the data are complete, valid, reliable and comprehensive, whether they have been collected in a timely manner and whether applied definitions are consistent (Box 10).

Box 10 – Challenges with regard to data quality

These challenges can be classified into six key aspects:

- **Completeness**, i.e. ideally, the data should include all patients, however, this is rarely the case. If data are missing, this should occur randomly and only occasionally. If missing data are too common, the data become unfit for assessing quality;
- **Validity**, i.e. the data should accurately reflect reality and should be free of bias and other errors;
- **Reliability**, i.e. repeated measurements by different data collectors, judges, or instruments, at different times and places, provide similar results;
- **Comprehensiveness**, the used database(s) should contain all relevant variables needed for analysis, such as diagnosis and therapeutic codes, pharmaceuticals, details from pathology and surgery reports, etc;
- **Timeliness**, i.e. the data are available for use without considerable delay;



- **Consistency**, i.e. the data are based on agreed definitions, and described exhaustively and exclusively.

Source: Mainz, 2003;²⁴⁵ Gurol-Urganci et al., 2017;²⁴⁸ Quentin et al., 2019²³⁹

Various data sources can be used for quality measurement. Routinely collected data, such as **health insurance data** (in Belgium e.g. data from the Intermutualistic Agency, IMA – AIM) and **hospital discharge data** (MZG – RHM, see also Box 5), can provide valuable data for process indicators. They have the advantage that they provide a good coverage of the population (i.e. limited selection bias), they are readily available and easily accessible in electronic form, and no additional efforts are required to collect them. Yet, fee schedules may be vague, as they are primarily intended for administrative and management purposes and not for quality assessment.^{249, 250} In addition, codes may be ‘used’ by healthcare professionals for other procedures than the ones intended (‘optimisation’), which may result in the over- or underestimation of some procedures.²⁵¹ But also, administrative databases often lack important information for quality measurement, such as patient reported outcomes (PROMs) and experiences (PREMs), or the extent of the multidisciplinary approach.^{249, 250}

Sometimes the original quality indicator needs to be adapted (slightly) so that the result can be calculated with administrative data. For instance, for the Belgian outpatient setting, there are only data publicly available on the pharmaceuticals that are purchased, not on the number of prescriptions nor on the effective intake by the patient. As a consequence, a process indicator like ‘proportion of adolescents with severe dysmenorrhea and/or endometriosis-associated pain, who *are prescribed* hormonal contraceptives or progestogens as first line hormone therapy’ will need to be re-phrased as ‘proportion of adolescents with severe dysmenorrhea and/or endometriosis-associated pain, who *purchased* hormonal contraceptives or progestogens as first line hormone therapy’. But then the question raises: does this rephrased indicator still denote quality? The rephrased quality indicator does not only assess the knowledge and prescription behaviour of the healthcare provider, but also, to some extent,

the patient’s (and parents’) preferences and initiative to purchase hormone therapy.

Disease-specific registries may also provide useful information for the calculation of quality indicator results (see also section 2.2.7). For example, to calculate the ‘Proportion of patients with endometriosis in whom imaging (US or MRI) in the diagnostic work-up for endometriosis is performed’, data for the denominator (i.e. the number of patients with a confirmed diagnosis of endometriosis) can be derived from a (population-based) registry. However, registries require significant investment in establishment and maintenance.²³⁹ Still, it has been suggested that it is possible to generate and feed disease-specific population registries from electronic health records,²⁵² which may significantly reduce the costs of data collection for registries.

Before using data collected in a registry for quality assessment, its **completeness** should be assessed. For instance, if data collection is performed on a voluntary basis, some healthcare professionals may opt to only register a subgroup of patients, which may have a major impact on the calculation of certain quality indicators, e.g. those on patient outcomes or on adverse events.²⁵³ Likewise, if registries are limited to inpatient data (such as the Swedish National Inpatient Register²⁵⁴), they will for instance not include patients (with endometriosis) whose treatment was (so far) restricted to the outpatient setting (e.g. patients treated solely with analgesia or hormone treatment), hence precluding the calculation of certain quality indicators.

Regardless of the database that is used, when quality of care among hospitals, regions, or countries, is compared or when evolutions over time are assessed, **classification systems** and **registration routines** should be **uniform**.²⁵⁵ Yet, at present, there is no validated classification system for endometriosis.⁶

But also, when outcomes (and certain processes) are compared between providers, important **confounders** (in particular ‘case-mix variables’) should be taken into account. For instance, the severity of disease (e.g. superficial vs. deep endometriosis), but also other coexisting conditions (e.g. diabetes) and/or life style factors (e.g. smoking, alcohol abuse) and/or socio-economic



background may influence the outcomes of care. Therefore, these factors should be documented so that they can be included in the analyses (i.e. 'risk adjustment' or 'case-mix adjustment').

6.3 Quality indicators on endometriosis

6.3.1 Assessment of processes of care

Based on the ESHRE 2014 guideline,³⁴ which included 83 recommendations, researchers from the Netherlands and Belgium selected together with an international panel of patients and medical professionals **seventeen key recommendations for endometriosis care** by, as a first step in the development of quality indicators.²⁵⁶ The authors of this KCE report proceeded with this work. We first identified the equivalent recommendations in the ESHRE 2022 guideline,³³ and then translated these 'quality goals' into 'measurement concepts' (Table 49 in Appendix 6.3). In a third step we assessed the **measurability** of the numerator and denominator of the quality indicators, **based on the currently available administrative databases in Belgium**, i.e. taking into account that there is (at present) no endometriosis registry.

The seventeen key recommendations from 2014 corresponded to fifteen recommendations included in the ESHRE 2020 guideline;^{33, 34} all quality goals related to processes of care. **As of today, none of the quality indicators can be calculated**, mainly because we do not have data on the number of patients with endometriosis and we cannot identify women with endometriosis from the administrative databases, unless they have been admitted in hospital (see section 4.1). For some indicators, additional information on the fertility status and/or the type or severity of endometriosis is needed, while it should be clear that 'a suspicion of [e.g.] deep endometriosis' is difficult to measure, hence will require re-phrasing of the indicator. For other quality indicators it should be discussed with clinical experts (and patients) whether the denominator should be restricted to patients with endometriosis-associated pain, which may better reflect quality of care, yet may hamper the measurability as additional information needs to be collected.

The tenth quality goal states 'The guideline development group (GDG) recommends that women with deep endometriosis are referred to a centre of expertise'. Based on hospital discharge data (MZG – RHM) patients who were diagnosed and treated in a different hospital (site) can be identified, yet based on these data patients being referred by the diagnostic team/hospital cannot be distinguished from patients who take that initiative themselves. Again, additional information needs to be collected to calculate that indicator.

The quality goals that assess the health care professionals' reflections ('consider the diagnosis of endometriosis [if] ...'), their task to counsel and inform patients ('counsel women with symptoms ...') as well as the shared decision-making approach cannot be measured as these activities are currently not recorded. The collection of PROMs and PREMS may provide some insights in these processes, but from the patient perspective.

Two further methodological considerations are essential when embarking on the quality assessment of endometriosis care in Belgium. First of all, as mentioned above, **thresholds (or targets) need to be defined**. Quality measures without an appraisal concept cannot indicate whether obtained results denote good or bad quality of care. For instance, which proportion of patients with endometriosis-related pain should receive NSAIDs or other analgesics (recommendation v), which proportion should receive hormone treatment (recommendation vi) and which proportion should receive surgery (recommendation ix) in order to reflect good quality of care? Before the calculation of any quality indicator, these thresholds should be defined for every indicator by a multidisciplinary group of clinical experts, patients and researchers.

Secondly, health insurance data in Belgium (e.g. IMA – AIM) are not directly linked with the indication (pathology) for which they are recorded, and the description of the (nomenclature) code is often not specific enough to identify this indication with certainty. For instance, code '459410-459421: MRI examination of the neck or thorax or abdomen or pelvis, at least three sequences, with or without contrast, with recording on optical or



electromagnetic support'^{ppp}, can be recorded for many other pathologies than endometriosis. Therefore, it will be necessary to restrict the selection of diagnostic and therapeutic procedures to **pre-specified time frames**, e.g. only interventions performed within x months around the date of diagnosis of endometriosis, so that procedures performed for other indications can be excluded to the maximum extent possible. This approach will indeed necessitate the definition of a 'date of diagnosis'.

6.3.2 Assessment of the patient-centredness of care

Health services should not only provide care that is effective^{qqq}, accessible, equitable, and safe, the care offered should also be patient-centred, i.e. 'respectful of and responsive to individual patient preferences, needs, and values and guided by patients' values'.²⁵⁷ Hence, quality indicators should also assess the latter dimension of quality.²³⁹

Important work on the assessment of the patient-centred dimension of endometriosis care has been performed within the framework of the European Network on Endometriosis (ENE), and coordinated by researchers from Leuven University, among others.^{30, 258-260} They developed the ENDOCARE questionnaire, a validated instrument to measure the patient-centredness of endometriosis care in secondary and specialized tertiary endometriosis clinics^{rrr, 30, 261} The ENDOCARE questionnaire does not only comprise the eight dimensions framework of patient-centred care as identified by Gerteis et al. (1993),²⁶² but also two dimensions that are similar for endometriosis care and for fertility care (Box 11).²⁶³

The authors recommend that health care professionals working in endometriosis reference centres pay attention to all ten dimensions when

interacting with patients with endometriosis.²⁶⁴ In addition, they advise endometriosis expert centres to **regularly** (at least yearly) **monitor all ten dimensions of patient-centred endometriosis care** with the ENDOCARE questionnaire and benchmark their results (adjusted for differences in case-mix) against those of the other centres.^{31, 264}

Box 11 – Dimensions of patient-centred care covered by the ENDOCARE questionnaire

The following ten dimensions are covered in the ENDOCARE questionnaire:

- Respect for patients' values, preferences and expressed needs;
- Coordination and integration of care;
- Information, communication and education;
- Physical comfort;
- Emotional support and alleviation of fear and anxiety;
- Involvement of family and friends;
- Continuity and transition;
- Access to care;
- Technical skills^{EF};
- Endometriosis clinic staff^{EF}.

EF: dimensions that are similar for endometriosis care and for fertility care.

Source: Dancet et al., 2011³⁰

^{ppp} 459410-459421: NMR-onderzoek van de hals of van de thorax of van het abdomen of van het bekken, minstens drie sequenties, met of zonder contrast, met registratie op optische of elektromagnetische drager - Examen d'IRM du cou ou du thorax ou de l'abdomen ou du bassin, minimum 3 séquences, avec ou sans contraste, avec enregistrement sur support soit optique, soit électromagnétique

^{qqq} Effective: adherent to an evidence base and results in improved health outcomes, based on need; efficient: in a manner which maximizes resource

use and avoids waste; accessible: timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need; equitable: delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status; safe: minimizing risks and harms.²⁵⁷

^{rrr} The ENDOCARE questionnaire has not been validated for primary health care settings. (Dancet, personal communication)



The ENDOCARE questionnaire was originally developed in three languages (i.e. Dutch, English and Italian),³⁰ but was later on reciprocally translated into six additional languages (i.e. Danish, Finnish, French, German, Spanish and Swedish).²⁶⁰ The ENDOCARE questionnaire has been used in several European countries to assess and compare patient-centredness of endometriosis care.^{30, 31, 259, 261, 265}

A systematic review of the literature on the patient-centredness of endometriosis care pointed to **three primary improvement targets** which were unmistakably reported as important and problematic: **respecting patients, believing patients, and timely diagnosis of endometriosis**.²⁵⁸ Further, a web-based survey across thirteen European countries^{sss} where 3,837 members of patients' associations completed the ENDOCARE questionnaire, revealed that the patient-centredness of care could be improved with respect to **'reaching a diagnosis quickly'** and **'physicians demarcating the stage of endometriosis complexity that they can treat and referring if need be'**. These aspects were consistently rated as of more-than-average importance and were negatively experienced by more than half of the European sample.²⁶⁰

6.3.3 Assessment of outcomes of care

As of today, none of the therapies for endometriosis are curative. They all have side effects, and recurrence occurs regularly after surgery or discontinuation of hormonal treatment.^{158, 166} Many patients with endometriosis experience an impaired quality of life (QoL). But, what is more, many of them continue to suffer from endometriosis-associated symptoms despite seemingly adequate medical and/or surgical treatment, and even though they have been managed in tertiary care centres.^{28, 166} This poses **important challenges to the assessment of the outcomes of care**, certainly when outcomes among various providers (e.g. hospitals, surgeons) are to be compared.

In the literature, several (clinical) outcomes have been suggested to assess the effectiveness of endometriosis care in clinical trials. Duffy et al. (2020) developed together with 116 healthcare professionals, 31 researchers and 206 patient representatives, who represented 29 countries, an **outcome set for future endometriosis research**, using a modified Delphi method and a modified nominal group technique.²⁶⁶ The core outcome set comprised three outcomes evaluating potential treatments for pain and other symptoms associated with endometriosis, eight outcomes evaluating potential treatments for infertility associated with endometriosis and two outcomes applicable to all trials, adverse events and patient satisfaction with treatment (Box 14 in Appendix 6.3).²⁶⁶

Patient complications after endometriosis surgery have been classified according to the Clavien-Dindo classification.^{187, 267} In other publications, recurrence, frequency of emergency room visits, and rate of opioid use, have also been suggested as outcome measures.^{158, 164}

They can all be translated into outcome indicators, but again, this will require the definition of a **measurement concept** (e.g. proportion of patients with (suspicion of) deep endometriosis who had endometriosis surgery, who were affected by adverse events) and an **appraisal concept** (i.e. a target). In addition, **explicit criteria for inclusion, exclusion, timeframe and setting** need to be defined.

Patient Reported Outcome Measures (PROMs), i.e. measuring health outcomes and experiences from the patients' perspectives, have also been studied in the context of endometriosis.²⁶⁸ A literature review revealed a catalogue of 48 PROMs used as tools to evaluate various dimensions of the impact of endometriosis (care) on patients.²⁶⁸ Recently, an international team of clinical experts and patient representatives developed through a modified Delphi study a set of patient-centred outcomes for use in routine endometriosis care which are relevant to all patient profiles.²⁶⁹ The final set comprises six PROMs covering domains of pain-related symptoms, symptomatic impact, work productivity, disease-related quality of life, sexual

^{sss} The thirteen European countries included Belgium, Denmark, Finland, France, Germany, Italy, Spain, Sweden, the Netherlands, the United

Kingdom, Austria, Ireland and Switzerland; the respondents self-reported to be surgically diagnosed with endometriosis.



activity, gastrointestinal symptoms and psychological impact, and ten Clinician Reported Outcome Measures (CROMs), measuring clinical, imaging and surgical indicators.

Generic PROMs^{ttt}, like the EQ-5D-5L^{uuu},²⁷⁰ the Short Form-36 version 2 (SF-36v2)^{vvv},²⁷² and the World Health Organization Quality of Life Instrument, Short Form (WHOQOL-BREF)^{www},²⁷⁴ as well as endometriosis-specific PROMs, like for instance, the Endometriosis Health Profile-30 items (EHP-30^{xxx}),¹⁹⁵ and the Endometriosis Health Profile-5 items (EHP-5),^{276, 277} have been used. Based on a systematic review of the literature, both the SF-36 and the EHP-30 have been recommended for the evaluation of HRQOL in women with endometriosis, as they perform better overall with regard to their strengths and weaknesses when compared to other scales.²⁷⁸

In the UK, outcome data are collected as part of the endometriosis registry that is required for certified endometriosis centres.¹⁶¹ The collected indicators include outcome data on pain, bowel function and symptoms, quality of life and surgical complications assessed prior to surgery and subsequently at 6, 12 and 24 months post-surgery. Quality of life is assessed by questionnaires such as the EuroQol 5D-3L or EuroQol Visual Analogue Score.²¹⁵ The type of surgery performed and other medical treatments are also registered.²¹⁵

Key points:

- **The scant evidence in the field of endometriosis diagnosis and treatment is reflected in the level of evidence of the 109 recommendations included in the ESHRE guideline 2022: none are based on high level of evidence, only eight on moderate level of evidence, while thirty were mainly based on the expertise and opinion of the Guideline Development Group;**
- **When quality of care is assessed, classification systems and registration routines should be uniform; yet, at present, there is no validated classification system for endometriosis;**
- **As of today, none of the process indicators proposed by an international panel of patients and medical professionals can be calculated based on the currently available administrative databases in Belgium; hence, additional data collection (e.g. registry) will be indicated;**
- **The ENDOCARE questionnaire, which is available in the three official languages (i.e. Dutch, French, and German), can be used to assess the patient-centredness of endometriosis care;**
- **The assessment of the outcomes of endometriosis care poses important challenges: none of the therapies for endometriosis are curative and despite seemingly adequate medical and/or surgical treatment, many individuals with endometriosis continue to suffer from endometriosis-associated symptoms.**

^{ttt} Generic PROMs are not specific to endometriosis or any other disease or condition, therefore they can be used to make comparisons between and within interventions as well as across different diseases and sectors of care.

^{uuu} EQ-5D-5L: a five-dimensional generic instrument, asking patients to rate their mobility, self-care, usual activities, pain/discomfort and anxiety/depression on a five-level scale.

^{vvv} SF-36v2: an eight-dimensional generic instrument of health-related quality of life (recall period 4 weeks), which allows to compare the examined population to a general standard population.²⁷¹

^{www} World Health Organization Quality of Life Instrument, Short Form (WHOQOL-BREF): a QoL measure that is reliable and valid for use in a diverse range of cultures.²⁷³

^{xxx} Endometriosis Health Profile (EHP-30): a questionnaire developed to measure the extent to which endometriosis has an impact on quality of life; the thirty questions can be divided into five subscales covering 'pain', 'control and powerlessness', 'social support', 'emotional wellbeing' and 'self-image'.²⁷⁵



7 DISCUSSION

In this report we read that between 2016 and 2020, 162 hospital admissions per 100 000 women were related to endometriosis. About three in four of these admissions were recorded in women of reproductive age (15-49 years old). In at least one in eight women who had endometriosis surgery, a subsequent endometriosis-related hospital admission was recorded in the following year(s). Interesting data, yet they only reflect the tip of the iceberg: hospital care offered to women with more severe disease and/or more severe symptoms.

Meanwhile, many data gaps regarding endometriosis care in Belgium remain.

We do not know how many Belgian citizens consult their general practitioner and/or gynaecologist with symptoms suspicious of endometriosis.

We do not know how many Belgian citizens have actually been diagnosed with endometriosis.

We do not know how many Belgian citizens take medical treatment for endometriosis.

We do not know how many Belgian citizens suffer every single day because of endometriosis, without or despite medical and/or surgical care.

From the patient testimonials we learn that once women with symptoms suspicious of endometriosis decide to seek professional care, many face multiple obstacles in the Belgian care landscape. Some patients report inadequate knowledge and expertise of health care providers, and being provided with wrong information or inappropriate advice. Just as problematic, they often feel not being taken seriously, with reported symptoms being normalised or minimised. They feel blamed or psychologized (e.g. 'it's all in your head').

Several patient needs were identified. First of all, patients voice the need for more expertise and accurate knowledge about endometriosis at all levels of health care, also in primary care. Patients' associations expressed their concern about the surgical expertise in Belgium, therefore they seek treatment abroad. But also, they express the need to be heard with empathy and respect. Patients demand that endometriosis care is coordinated by multidisciplinary endometriosis teams, in order to be relieved from the pressure to organize this care themselves. They ask for a comprehensive care plan, so that informed choices can be made and realistic expectations about the future can be shaped.

To that end, several bottom-up initiatives have been taken in Belgian hospitals. From the seventy-seven hospitals that completed the online survey, thirty indicated they had set up an 'endometriosis clinic'. Yet, seven of them admit that they do not organise multidisciplinary meetings where the diagnosis and treatment plan of individual patients are discussed. Thirteen self-reported endometriosis clinics see twenty or fewer new patients per month. But, what is more, individuals in need of endometriosis care will have a hard time finding some of these initiatives. Only ten self-reported endometriosis clinics provide on their hospital website^{yyy} background information on endometriosis together with the notice of a multidisciplinary endometriosis team/centre. Several self-reported endometriosis clinics do not present the team members. In one of them the team is limited to a gynaecologist and an abdominal surgeon. Some even fail to inform how the endometriosis clinic can be contacted for a first appointment. In short, not all these bottom-up initiatives comply with the key elements that are required in endometriosis care: 1) personalised care, 2) a multidisciplinary approach, 3) centres of expertise with specialists with thorough training and extensive experience, and 4) quality assurance through transparent recording and reporting of outcomes.

^{yyy} Based on an exploration of hospital websites in November-December 2023.



Adequate 'guidance' through regulation and legislation - but also funding - is mandatory to support initiatives already taken and to guarantee minimal (para)medical staffing, infrastructural and other standards. All citizens with (a suspicion of) endometriosis should have access to multidisciplinary and comprehensive high-quality endometriosis care, based on the prevailing scientific evidence and tailored to the needs at that time of their life course. Policy makers should also reflect whether endometriosis care, and more precisely surgery for (deep) endometriosis, should be offered in each Belgian hospital. This is currently the case, with some hospitals reporting that they do not perform more than five surgeries for deep endometriosis per year. On the other hand, care should be organised in such a way that waiting times are acceptable.

Inspired by initiatives taken in Australia, Denmark, Germany, France, the Netherlands and the UK, informed by proposals voiced in the hospital survey, based on the discussions we had with clinical experts during two face-to-face meetings, and giving consideration to the patients' needs, recommendations for the organization of endometriosis care in Belgium have been developed. They have been presented and discussed in several meetings with relevant stakeholders, and based on their input, they were further refined.

These policy recommendations (which are presented in the Dutch and French syntheses) have been developed bearing the prevailing paradigms on endometriosis and endometriosis care in mind. Yet, given the many unknowns with regard to the prevalence, diagnosis, pathogenesis, and treatment efficacy of endometriosis (care), the care organization will require thoughtful adaptations when these mysteries are being unravelled.

In all fairness, some limitations of the present report need to be listed. Firstly, due to the limitations of the available data, we restricted the scope of this study to specialist endometriosis care. A linkage of the available hospital discharge and billing data, with data on ambulatory care consumption could have portrayed pre- and posthospital care. But, given the lack of endometriosis-specific codes in the fee schedule, it would not have been possible to estimate based on this extended dataset the diagnostic delay or reveal in an accurate way the health care labyrinth citizens are confronted

with in their quest to find appropriate endometriosis care. Moreover, it would not have been possible to identify individuals with endometriosis who have not been admitted in hospital, and their medical encounters. Hence, any estimate of ambulatory care consumption would have been inaccurate.

But also the presented hospital data should be interpreted with caution as no validation of the data was performed. In addition, a probably large but unknown proportion of these hospitalisations is related to adenomyosis, which is a different yet often co-existing clinical entity. And finally, given the lack of dedicated endometriosis fee codes, it was not possible to unravel which type of endometriosis surgery was performed.

Considering this lack of comprehensive endometriosis-related health care consumption data, we deliberately did not perform any costing analysis.

Thirdly, due to time constraints, it was not possible to set up interviews or focus group discussions with patients and other stakeholders, as these research methods require ethical approval. Yet, we gave a voice to patients through the review of the dedicated international literature and the analysis of the testimonials collected by Belgian patients' associations. In chapter 3 we ask the reader to keep in mind that the sample is the result of self-selection, in response to patients' associations' call to give a full account of the struggles endometriosis brings about. Thus, individuals with limited symptoms and/or positive experiences with endometriosis care may not have felt incentivised to submit their experiences. Yet, from the perspective of our main research objective (how can endometriosis care be improved in Belgium), the testimonials from women with severe symptoms and/or inadequate medical encounters are actually very valuable.

Fourthly, in this report we did not elaborate on the importance of adequate menstrual health education so that young girls and their significant others understand what is 'normal' and what needs further medical investigation. Still, from the testimonials we learned that young girls are a very vulnerable subgroup with own needs. We also did not cover education and increased awareness about endometriosis, nor the promotion of health literacy. Further research and initiatives are indicated to make headway with these important themes in multiple groups: adolescents (girls and boys) and parents, patients, health care professionals, schools, higher education institutions



and universities, employers and workplace human resources departments, sport clubs and others. Within these initiatives special attention is indicated to address also residents from culturally and linguistically diverse backgrounds.

Lastly, endometriosis may have a profound impact on all aspects of an individual's life, including sexual and social relationships, self-identity and body image, educational and employment opportunities, sport, quality of life. The policy recommendations listed in this report are restricted to the health care system. Yet, in order to improve the quality of life of women affected by endometriosis and to reduce inequity as a result of endometriosis, actions beyond the health care setting will also be needed (e.g. to adapt school and working conditions by providing more flexibility).



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■ APPENDICES

APPENDIX 1. BACKGROUND

Appendix 1.1. Licensing standards for reproductive medicine care programmes

Box 12 – Licensing standards for reproductive medicine care programmes – Main outlines

Reproductive medicine care programme (centre) A:

- **Tasks of the care programme** include infertility workup and determining ART indications; informing patients about fertility treatments and associated costs; offering them information brochures; controlled ovarian hyperstimulation; gamete retrieval and transport to B centres; psychological and social support of patients.
- **Infrastructure:** The care programme should be integrated in a hospital where reconstructive and endoscopic surgery is offered and should have specific equipment for gynaecological ultrasound;
- **The medical coordination** of the centre is performed by a specialist in gynaecology-obstetrics with at least three years' experience in reproductive medicine, who works exclusively at the hospital.
- **Medical expertise:**
 - The coordinator is assisted by at least one specialist in gynaecology-obstetrics with the same proven and maintained competence, who also works exclusively in this hospital;
 - A medical specialist in andrology should be working in the hospital where the care programme is integrated.
- Every A centre must have a formal **collaboration agreement** with at least one B centre. The agreement must specify, among others, the organisation of a joint discussion of cases and the organisation of safe transport of gametes from centre A to centre B.



- **Registration:** in order to monitor the quality of care, data on the trajectory of every patient (e.g. age of the patient, IVF indication, number of oocyte simulations, number of clinical pregnancies achieved, number of children born alive achieved) are prospectively registered online (without the option for *a posteriori* corrections).

In addition to the criteria for the A centres, the licensing standards for the **Reproductive medicine care programmes (centres) B** include:

- **Additional tasks:** in vitro fertilisation techniques (in vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI)), embryo transfer, gamete and embryo cryopreservation.
- **Infrastructure:**
 - The care programme should include an ART laboratory (capable of achieving in vitro fertilisation and of treating and preserving in vitro gametes and embryos).
 - The hospital should offer microsurgery.
- **Expertise:** A medical specialist in reproductive endocrinology should be working in the hospital.
- Every B centre must have a formal **collaboration agreement** with a recognised centre for human genetics in Belgium.

Source: Royal Decree of 15 February 1999⁹⁷



Appendix 1.2. Overview of care programmes (centres) A and B for reproductive medicine

Table 15 – Overview of care programmes (centres) A and B for reproductive medicine

Network	A centre (site number) N=16	B centres (site number) N=18
BRIANT Vzw	- Imelda Ziekenhuis, Bonheiden (2040)	
CHORUS	- Chirec - Hôpital Delta, Oudergem (6140)	- UMC Sint-Pieter – campus Hallepoort, Brussel (1520) - Erasmusziekenhuis ULB – campus Erasmus, Anderlecht (4210)
CUROZ Vzw		- Universitair Ziekenhuis Brussel, Jette (4200)
E17 Ziekenhuisnetwerk Vzw	- AZ Groeninge – campus Kennedylaan, Kortrijk (1090)	
ELIPSE, Réseau Hospitalier Universitaire		- Hôpital de la Citadelle – site Citadelle, Liège (3410)
Ziekenhuisnetwerk Gent Vzw	- AZ Sint-Lucas, Gent (1630) ^{zzz}	- Universitair Ziekenhuis Gent (3850) - AZ Jan Palfijn, Gent (1610) ^{aaaa}
ZAS (Ziekenhuis aan de Stroom)	- GZA- Ziekenhuizen, campus St-Augustinus, Wilrijk (1290)	- Ziekenhuisnetwerk Antwerpen - campus Middelheim, Antwerpen (2000)
Réseau Hospitalier Clinique Locorégional H.Uni	- Clinique Saint Pierre, Ottignies (1730) - Kliniek Sint-Jan – campus Kruidtuin, Brussel (1310)	- Universitair Ziekenhuis St.-Luc, Sint-Lambrechts-Woluwe (4190)
HELIX Vzw	- AZ Klina – campus AZ Klina, Brasschaat (3450)	- Universitair Ziekenhuis Antwerpen, Edegem (4220)
HELORA Réseau Hospitalier	- CHU HELORA – site Kennedy Mons, Mons (2730)	
Réseau HUmani Santé Charleroi/Chimay	- CHU Charleroi – site Hôpital Civil Marie Curie, Lodelinsart (3130)	

^{zzz} Collaboration agreement ('associatie'/'association') with AZ Elisabeth, Zottegem (1900)

^{aaaa} Collaboration agreement ('associatie'/'association') with OLV, Aalst (1780)



Network	A centre (site number) N=16	B centres (site number) N=18
KEMPEN Vzw	- AZ Turnhout - campus Sint-Jozef, Turnhout (2100)	
KOM (Kust – Ommeland – Meetjesland) Vzw		- AZ Sint-Jan – campus Sint-Jan, Brugge (1010) ^{bbbb}
MIRA Vzw	- Vitaz – campus Sint-Niklaas, Sint-Niklaas (1860)	
Réseau « MOVE »		- Groupe Santé CHC – site CHC MontLégia, Liège (6200)
Ziekenhuisnetwerk Noord-Oost Limburg Vzw		- Ziekenhuis Oost-Limburg - campus Sint-Jan, Genk (3560) ^{cccc}
PHARE Asbl	- Centre Hospitalier de Wallonie Picarde - site Union, Tournai (2830)	
PLEXUS Vzw		- Regionaal Ziekenhuis Heilig Hart, Leuven (1360) - UZ Leuven – campus Gasthuisberg, Leuven (4230)
Réseau Hospitalier Namurois (R.H.N.)	- CHU-UCL Namur – site Godinne, Mont-Godinne (3280)	- CHR Sambre et Meuse – site Meuse, Namur (3300)
TRiaz Vzw	- AZ Delta – campus Rumbeke, Roeselare (6210)	
RHCL VIVALIA		- Centre Hospitalier Centre Ardenne – site Libramont, Libramont (3240)
Ziekenhuisnetwerk Andreaz	- Jessa Ziekenhuis - campus Virga Jesse, Hasselt (3590) ^{dddd}	
No network specified in FOD-SPF data dd 1 February 2024		- Grand Hôpital de Charleroi – site Notre Dame, Charleroi (3100)

^{bbbb} Collaboration agreement ('associatie'/'association') with AZ Sint-Lucas, Brugge (1000)

^{cccc} Collaboration agreement ('associatie'/'association') with Jessa Ziekenhuis, Virga Jesse, Hasselt (3590)

^{dddd} Collaboration agreement ('associatie'/'association') with Ziekenhuis Oost-Limburg, Sint-Jan (3560)



Network	A centre (site number) N=16	B centres (site number) N=18
(https://www.health.belgium.be/nl/gezondheid/organisatie-van-de-gezondheidszorg/delen-van-gezondheidsgegevens/gezondheidszorginstellingen)		- CHIREC - SARE Site Hôpital de Braine-l'alleud, Braine-l'alleud (1760)

Note: The hospitals are listed according to the hospital network to which they belong; the collaboration agreements between A and B centres is not mentioned.

Appendix 1.3. Overview of hospitals with a multidisciplinary pain centre

Table 16 – Overview of the hospitals with a multidisciplinary pain centre

License number	Hospital	Place
009	Ziekenhuisnetwerk Antwerpen Vzw	2060 Antwerpen
010	Grand Hôpital de Charleroi	6060 Gilly
012	AZ ST. Blasius	9200 Dendermonde
020	Centre Hospitalier Peltzer - La Tourelle	4800 Verviers
032	Algemeen Ziekenhuis Alma	9900 Eeklo
039	Clin. Universitaires U.C.L. de Mont-Godinne	5530 Mont-Godinne
049	A.Z. St.-Jan Brugge-Oostende	8000 Brugge
057	Jan Yperman Ziekenhuis	8900 Ieper
063	Algemeen Ziekenhuis Turnhout	2300 Turnhout
077	Centre Hospitalier Universitaire Brugmann	1020 Bruxelles
096	Centre Hospitalier Universitaire Tivoli	7100 La-Louvière
097	H.-Hartziekenhuis V.z.w.	2500 Lier

License number	Hospital	Place
099	GZA-Ziekenhuizen	2610 Wilrijk
104	Sint-Jozefkliniek	2880 Bornem
117	H.- Hartziekenhuis Roeselare - Menen Vzw	8800 Roeselare
126	Onze Lieve Vrouw Ziekenhuis	9300 Aalst
143	Universitair Ziekenhuis Brussel	1090 Brussel
152	Centre Hospitalier Chrétien	4000 Liège
166	Clinique Et Maternite Ste.-Elisabeth	5000 Namur
168	Vivalia - Centre Hospitalier de l'Ardenne	6800 Libramont
217	Algemeen Ziekenhuis St. Elisabeth	9620 Zottegem
243	Jessa ziekenhuis	3500 Hasselt
247	Centre Hospitalier de Mouscron	7700 Mouscron
290	Algemeen Ziekenhuis St. Lucas	9000 Gent
300	Universitair Ziekenhuis Antwerpen	2650 Edegem
322	Universitaire Ziekenhuizen K.U.L.	3000 Leuven
371	Ziekenhuis Oost - Limburg	3600 Genk
403	Cliniques Universitaires St. Luc	1200 Bruxelles



License number	Hospital	Place
406	Hôpital Erasme	1070 Bruxelles
412	Centre Hospitalier Regional de la Citadelle	4041 Milmort
525	Algemeen Ziekenhuis Damiaan	8400 Oostende
595	Algemeen Ziekenhuis Nikolaas	9100 Sint-Niklaas
670	Universitair Ziekenhuis Gent	9000 Gent
682	A.Z. Monica	2100 Deurne
707	Centre Hospitalier Universitaire de Liège	4000 Liège

Source: Federal Public Service Health, Food Chain Safety and Environment
(https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_fille/pijnlijstzkhcentrummulti.pdf)

Appendix 1.4. Licensing standards for multidisciplinary centres for the treatment of chronic pain (MPC)

Box 13 – Licensing standards for multidisciplinary centres for the treatment of chronic pain (MPC) – Main outlines

- The following medical disciplines should be present in the medical staff of the multidisciplinary team: anaesthesia, rheumatology or physiotherapy and rehabilitation, neurosurgery or neurology, psychiatry. If none of these disciplines also has a certificate for rehabilitation, someone else with a certificate for rehabilitation should be available in the hospital.
- The coordinator of the multidisciplinary team should be specialised in anaesthesia, physiotherapy, neurosurgery or neurology, should have an additional training in algology and should have at least three years of experience in this field. The coordinator of the MPC should have at least a 0.75 FTE appointment in the hospital and at least 0.4 FTE in the MPC.
- Multidisciplinary team meetings are organised at least twice a month.
- The non-medical staff members are: a nurse (0.8 FTE), psychologist (0.8 FTE), physiotherapist (0.8 FTE), social worker or social nurse (0.5 FTE) and occupational therapist (0.5 FTE).



Appendix 1.5. Examples of Belgian disease-specific registries

Table 17 – Selection of Belgian disease-specific registries

Name; inception	Level; funding	Population	Purpose	Primary outcomes	Comments
Belgian Cancer Registry (BCR); 1983	National level; Funding by federal authorities through federal public services (SPF) and RIZIV – INAMI, federated authorities, non-profit organizations (e.g. Foundation against Cancer)	Nationwide, all patients with a cancer diagnosis	Registering all new cancer diagnoses in Belgium and their follow-up; Quality improvement initiatives for cancer patients	Incidence, prevalence, mortality, and relative survival for all invasive tumours	The BCR database is considered complete at the national level from the year 2004 onwards. Allows linkage with other data based on citizens' unique social security number.
Initiative for Quality Improvement and Epidemiology in Children and Adolescents with Diabetes (IQECAD); 2009	National level, managed by Sciensano; Funded by RIZIV – INAMI	Patients (about 3000) of the 15 multidisciplinary paediatric diabetes centres (PDCs), which are recognised by RIZIV – INAMI	2-yearly audit of PDCs	Primarily evolution of HbA1c; Several other process – and outcome indicators	Recognition of multidisciplinary centres is dependent on reporting. Evaluation reports are publicly available.
Belgian Pilot Spine Registry; 2018	Registry was initiated by RIZIV – INAMI, in collaboration with Spine Society of Belgium (professional scientific society); Funded by RIZIV – INAMI	Both surgical and conservatively treated patients within 15 participating hospitals	Preparation for nation-wide implementation in a second stage, international benchmarking	Spine Tango form preoperatively, 3 – 6 months, 1-2 years postoperatively; Includes PROMs (EQ-5D/COMI)	Surgical registry
Evaluation of Ambulatory Care Quality (EVACQ); 2009	National level, managed by Sciensano; Convention between RIZIV – INAMI and Sciensano	Care trajectory for diabetes type 2 and chronic kidney insufficiency within 100 recognised diabetes centres	Ambulatory care evaluation		Evaluation reports are publicly available
The Central Registry of Rare Diseases; 2012	National, set up by Sciensano;	All Belgian patients with a rare disease. At present, data are	Epidemiology, care policy, quality assurance, research, administration		



Name; inception	Level; funding	Population	Purpose	Primary outcomes	Comments
	Funded by RIZIV – INAMI	collected only at the centres for medical genetics.			
Belgian Neuromuscular Diseases Registry (BNMDR); 2008	National, managed by Sciensano in collaboration with the seven neuromuscular reference centres; Funded by RIZIV – INAMI	All patients diagnosed with one of the predefined 62 neuromuscular disease groups, followed at a neuromuscular reference centre	Assess incidence, research for new treatments	Demographics, ACTIVLIM questionnaire	
Belgian Cystic Fibrosis Registry; 1999	National, managed by Sciensano in collaboration with the 7 cystic fibrosis (CF) reference centres; Funded by RIZIV – INAMI	Coverage of almost all the patients with CF cared for in Belgium	Study epidemiological aspects of the disease; Benchmarking per centre, aim to improve the quality of care		Within the framework of the “CF-Convention”; Evaluation reports are publicly available

Note: This table is not intended to provide an exhaustive overview of disease-specific registries in Belgium as for instance not all registries on rare diseases are included; RIZIV – INAMI: National Institute for Health and Disability Insurance; EQ-5D: EuroQol-5D; COMI: Core Outcome Measures Index for the neck; ACTIVLIM: measure of activity limitations in children and adults with neuromuscular disorders.



Appendix 1.6. RIZIV-INAMI conventions

Table 18 – Non-exhaustive list of RIZIV-INAMI conventions

Group	Conventions
Respiratory diseases	Respiratory rehabilitation Respiration support Oxygen therapy at home Cardiorespiratory monitoring of babies
Conditions of the blood- and immunity system	Haemophilia AIDS Chronic fatigue syndrome
Endocrine and metabolic conditions	Diabetes Rare monogenetic metabolic diseases Cystic fibrosis
Cardiac conditions	
Mental and neurological disorders	Refractive epilepsy Mental disorders in adults (schizophrenia, anxiety disorder, autism, ...) Mental disorders
Musculoskeletal and neurological diseases and congenital disorders	Neuro-musculoskeletal diseases, Cerebral palsy Spina bifida
Paediatric diseases	Child nephrology Morbid obesity Consequences of maltreatment of children and adolescents
Sensory disorders	Visual disorders Hearing disorders



Appendix 1.7. Initiatives on endometriosis in Belgium

Table 18 – Non-exhaustive list of initiatives taken by patients and patients' associations on endometriosis in Belgium

Organisation	Examples of initiatives
Toi Mon Endo a.s.b.l. ^{bb}	- Raise awareness and provide tools for girls, women, the general public, as well as professionals regarding endometriosis (e.g. presentation of the movie 'Below The Belt', produced by Hillary Rodham Clinton, Rosario Dawson, Corinne Foxx & Mae Whitman, financed by the Commission of the French Community ('Commission communautaire française' (CoCof), a project to raise awareness on endometriosis, financed by the government of the Federation Brussels Wallonia (French-speaking community – Fédération Wallonie-Bruxelles).³⁶ - Provide support and guidance to individuals living with endometriosis through brochures, together with partners (e.g. with Hôpital Universitaire de Bruxelles (H.U.B.)) - Create a positive, compassionate, and resilient community around endometriosis, bringing people together - Organisation of endometriosis awareness events in 5th and 6th year of secondary schools.²⁷⁹
Endométriose Belgique a.s.b.l. ^{aa}	- Presentations at (health) conferences²⁸⁰ - Forum (space for exchange) between women with endometriosis²⁸¹ - Networking with different stakeholders.²⁸¹
Behind Endo (Stories) vzw ^{cc}	- National awareness campaigns 'Geef endometriose een gezicht' (2023) and upcoming 'geef Endo een stem' (2024)²⁸² - Provision of tips to make daily life with endometriosis bearable via webinars, blogs and a member platform²⁸² - Leaflet distributed to the sickness funds with information on endometriosis and action points in supporting patients with endometriosis (in collaboration with ENDO awareness BE-NL)
ENDO awareness BE-NL vzw	- Collection of patient testimonials²⁸³ - Open letter about the shortcomings in endometriosis care and possible action points to improve endometriosis care; this letter was directed to policymakers and health care professionals, but also to be informative for patients and their relatives.²⁸⁴ - Provision of medical information about the disease, the symptoms, the diagnosis, and the treatment, and the perceived need for treatment abroad.²⁸⁵ - Leaflet distributed to the sickness funds with information on endometriosis and action points in supporting patients with endometriosis (in collaboration with Behind Endo (Stories) vzw)
Other	MyEndo, documentary on a patient suffering from endometriosis ²⁸⁶



APPENDIX 2. PATIENT PERSPECTIVES ON ENDOMETRIOSIS

Appendix 2.1. Search strategies on patient perspectives

Appendix 2.1.1. Medline

Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to September 22, 2023>>	
Date	22 September 2023	
Search strategy		Number of hits
1	endometriosis/	25770
2	adenomyosis/	1274
3	1 or 2	26673
4	(endometriosis#s or endometrioma? or adenomyosis#s or adenomyoma? or adenometritis#s or adenomyositis#s or adenomyometritis#s).ti,ab,kf.	32982
5	3 or 4	36167
6	Patient Preference/	10746
7	Patient Satisfaction/	89728
8	Patient Participation/	29552
9	Perception/	43714
10	6 or 7 or 8 or 9	168448
11	patient?.ab,ti,kf.	8200734
12	perspective?.ab,ti,kf.	457934
13	experience?.ab,ti,kf.	1372302
14	satisfaction?.ab,ti,kf.	184662
15	perception?.ab,ti,kf.	342753
16	viewpoint?.ab,ti,kf.	42936
17	opinion?.ab,ti,kf.	131854
18	feedback?.ab,ti,kf.	179027



Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to September 22, 2023>>	
19	voices.ab,ti,kf.	10927
20	voicing.ab,ti,kf.	1751
21	insight?.ab,ti,kf.	644824
22	stories.ab,ti,kf.	15924
23	narrative?.ab,ti,kf.	76553
24	testimonials.ab,ti,kf.	559
25	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24	3055762
26	(patient? adj2 (perspective? or experience? or satisfaction? or perception? or viewpoint? or opinion? or feedback? or voices or voicing or insight? or stories or narrative? or testimonials)).ab,ti,kf.	221307
27	10 or 26	351167
28	5 and 27	449
29	limit 28 to yr="2013-2023"	259
30	remove duplicates from 29	257

Appendix 2.1.2. Cochrane

Database	Cochrane	
Date	26 September 2023	
Search strategy		Number of hits
#1	[mh ^"endometriosis"]	1208
#2	[mh ^"adenomyosis"]	72
#3	#1 or #2	1273
#4	(endometriosis or endometrioma? or adenomyosis or adenomyoma? or adenometritis or adenomyositis or adenomyometritis):ab,ti	3156
#5	#3 or #4	3266
#6	[mh ^"Patient Preference"]	1217

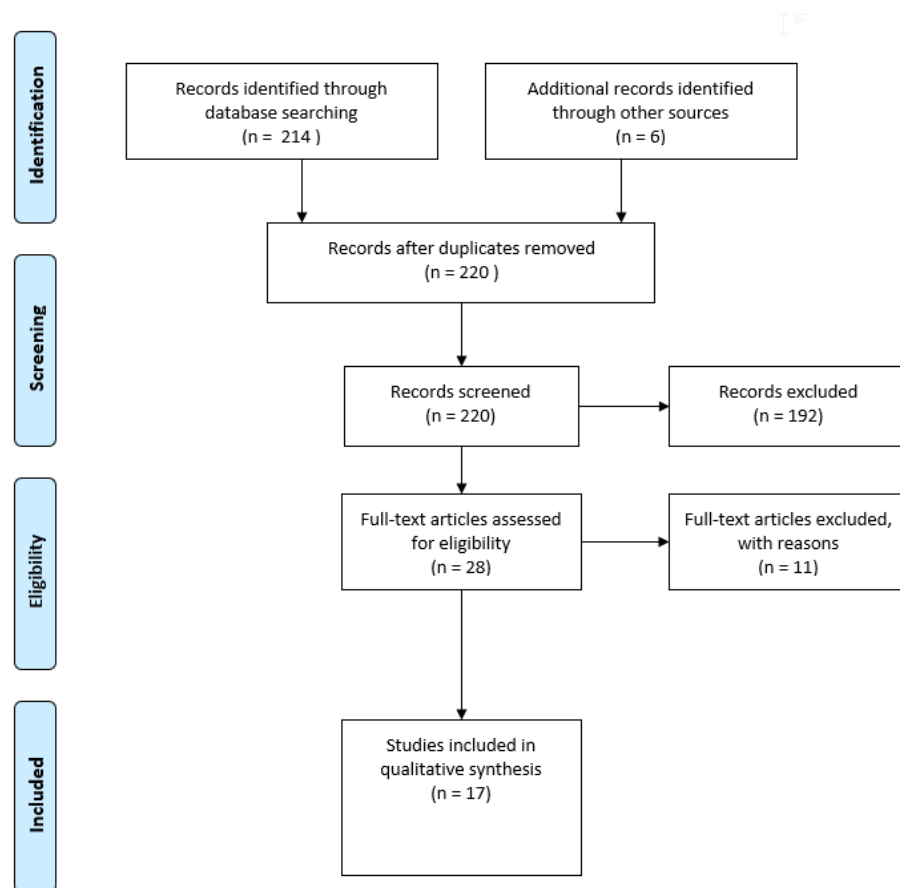


Database	Cochrane	
#7	[mh ^"Patient Satisfaction"]	14789
#8	[mh ^"Patient Participation"]	2067
#9	[mh ^"Perception"]	2458
#10	#6 or #7 or #8 or #9	19941
#11	(patient? NEAR/2 (perspective? or experience? or satisfaction? or perception? or viewpoint? or opinion? or feedback? or voices or voicing or insight? or stories or narrative? or testimonials)):ab,ti,kw	61117
#12	#10 or #11	65659
#13	#5 and #12	97
#14	#13 with Cochrane Library publication date Between Jan 2013 and Dec 2023, in Cochrane Reviews, Trials	80



Appendix 2.2. PRISMA flow chart

Figure 11 – PRISMA flow diagram





Appendix 2.3. List of included studies

Year	Publication
2023	Ellis, K., D. Munro, et al. (2023). "Dismissal informs the priorities of endometriosis patients in New Zealand." <i>Front Med (Lausanne)</i> 10 : 1185769.
2023	Gouesbet, S., M. Kvaskoff, et al. (2023). "Patients' Perspectives on How to Improve Endometriosis Care: A Large Qualitative Study Within the ComPaRe-Endometriosis e-Cohort." <i>J Womens Health (Larchmt)</i> 32 (4): 463-470.
2023	Kocas, H. D., L. R. Rubin, et al. (2023). "Stigma and mental health in endometriosis." <i>Eur J Obstet Gynecol Reprod Biol X</i> 19 : 100228.
2023	Mikesell, L. and A. C. Bontempo (2023). "Healthcare Providers' Impact on the Care Experiences of Patients with Endometriosis: The Value of Trust." <i>Health Commun</i> 38 (10): 1981-1993.
2022	Ellis, K., D. Munro, et al. (2022). "The experiences of endometriosis patients with diagnosis and treatment in New Zealand." <i>Front Glob Womens Health</i> 3 : 991045.
2022	Gehenne, L., A. Parent, et al. (2022). "[Living with endometriosis, sexual experiences of patients and their partners: A French qualitative study]." <i>Gynecol Obstet Fertil Senol</i> 50 (1): 69-74.
2022	Hudson, N. (2022). "The missed disease? Endometriosis as an example of 'undone science'." <i>Reprod Biomed Soc Online</i> 14 : 20-27.
2022	Rossi, V., R. Galizia, et al. (2022). "Endometriosis and Sexual Functioning: How Much Do Cognitive and Psycho-Emotional Factors Matter?" <i>Int J Environ Res Public Health</i> 19 (9).
2022	Strömberg, C., M. Olovsson, et al. (2022). "Age-related differences in experienced patient-centred care among women with endometriosis." <i>J Obstet Gynaecol</i> 42 (7): 3356-3361.
2022	Wren, G. and J. Mercer (2022). "Dismissal, distrust, and dismay: A phenomenological exploration of young women's diagnostic experiences with endometriosis and subsequent support." <i>J Health Psychol</i> 27 (11): 2549-2565.
2021	Missmer, S. A., F. F. Tu, et al. (2021). "Impact of Endometriosis on Life-Course Potential: A Narrative Review." <i>Int J Gen Med</i> 14 : 9-25.
2021	Rowe, H. J., K. Hammarberg, et al. (2021). "Improving clinical care for women with endometriosis: qualitative analysis of women's and health professionals' views." <i>J Psychosom Obstet Gynaecol</i> 42 (3): 174-180.
2021	van der Zanden, M., L. de Kok, et al. (2021). "Strengths and weaknesses in the diagnostic process of endometriosis from the patients' perspective: a focus group study." <i>Diagnosis (Berl)</i> 8 (3): 333-339.
2020	Della Corte, L., C. Di Filippo, et al. (2020). "The Burden of Endometriosis on Women's Lifespan: A Narrative Overview on Quality of Life and Psychosocial Wellbeing." <i>Int J Environ Res Public Health</i> 17 (13).
2018	Aerts, L., L. Grangier, et al. (2018). "Psychosocial impact of endometriosis: From co-morbidity to intervention." <i>Best Pract Res Clin Obstet Gynaecol</i> 50 : 2-10.
2018	Chauvet, P., C. Guiguet-Auclair, et al. (2018). "Feelings and expectations in endometriosis: Analysis of open comments from a cohort of endometriosis patients." <i>J Gynecol Obstet Hum Reprod</i> 47 (7): 281-287.
2018	Hållstam, A., B. M. Stålnacke, et al. (2018). "Living with painful endometriosis - A struggle for coherence. A qualitative study." <i>Sex Reprod Healthc</i> 17 : 97-102.



APPENDIX 3. ENDOMETRIOSIS-RELATED HOSPITAL ADMISSIONS IN BELGIUM - ADDITIONAL RESULTS

Appendix 3.1. Results at the national level

Table 19 – Number of endometriosis-related hospital admissions in 2016 – 2020, by type of diagnosis and type of stay

	2016 N=9 674		2017 N=9 363		2018 N=9 677		2019 N=10 093		2020 N=8 097		Total N=46 904	
Type of stay	D N (%)	I N (%)	D N (%)	I N (%)	D N (%)	I N (%)	D N (%)	I N (%)	D N (%)	I N (%)	D N (%)	I N (%)
Principal diagnosis	1 285 (26.0%)	3 666 (74.0%)	1 211 (25.7%)	3 504 (74.3%)	1 246 (24.9%)	3 751 (75.1%)	1 316 (26.1%)	3 731 (73.9%)	1 212 (29.2%)	2 934 (70.8%)	6 270 (26.3%)	17 586 (73.7%)
Secondary diagnosis	1 386 (29.3%)	3 337 (70.7%)	1 183 (25.5%)	3 465 (74.5%)	1 324 (28.3%)	3 356 (71.7%)	1 528 (30.3%)	3 518 (69.7%)	1 204 (30.5%)	2 747 (69.5%)	6 625 (28.7%)	16 423 (71.3%)
Total	2 671 (27.6%)	7 003 (72.4%)	2 394 (25.6%)	6 969 (74.4%)	2 570 (26.6%)	7 107 (73.4%)	2 844 (28.2%)	7 249 (71.8%)	2 416 (29.8%)	5 681 (70.2%)	12 895 (27.5%)	34 009 (72.5%)

D: day-care; I: inpatient

Classification of endometriosis-related hospital admissions

Almost all (92.8%) hospital admissions with endometriosis as principal diagnosis were classified in the Medical Diagnostic Category (MDC, version 34) 13, i.e. 'Diseases and disorders of the female reproductive system' (Table 20). The respective proportion of hospital admissions with endometriosis as one of the secondary diagnoses classified in MDC 13 was

67%. The other frequently recorded MDCs for hospital admissions with endometriosis as one of the secondary diagnoses was MDC 'Rehabilitation, aftercare, other factors influencing health status and other health service contacts' (MDC 23, 12.1%) which includes rehabilitation and other postoperative readmissions, 'Diseases and disorders of the digestive system' (MDC 06, 6.7%) and 'Pregnancy, childbirth and the puerperium'^{eeee} (MDC 14, 3.3%).

^{eeee} Puerperium is the period of adjustment after childbirth during which the mother's reproductive system returns to its normal prepregnant state. It

generally lasts six to eight weeks and ends with the first ovulation and the return of normal menstruation.

**Table 20 – Classification of endometriosis-related hospital admissions into Medical Diagnostic Categories**

Medical Diagnostic Category (MDC)	Principal diagnosis N (%)	Secondary diagnosis N (%)	Total N (%)
13 - Diseases and Disorders of the Female Reproductive System	2 2129 (92.8%)	15 439 (67%)	37 568 (80.1%)
23 - Rehabilitation, Aftercare, Other Factors Influencing Health Status and Other Health Service Contacts		2 787 (12.1%)	2 787 (5.9%)
06 - Diseases and Disorders of the Digestive System	1002 (4.2%)	1 543 (6.7%)	2 545 (5.4%)
14 - Pregnancy, Childbirth and the Puerperium		758 (3.3%)	758 (1.6%)
09 - Diseases and Disorders of the Skin, Subcutaneous Tissue and Breast	385 (1.6%)	209 (0.9%)	594 (1.3%)
00 - Residual Group	340 (1.4%)	200 (0.9%)	540 (1.2%)
11 - Diseases and Disorders of the Kidney and Urinary Tract		381 (1.7%)	381 (0.8%)
17 - Lymphatic, Hematopoietic, Other Malignancies, Chemotherapy and Radiotherapy		293 (1.3%)	293 (0.6%)
07 - Diseases and Disorders of the Hepatobiliary System and Pancreas		228 (1%)	228 (0.5%)
08 - Diseases and Disorders of the Musculoskeletal System and Connective Tissue		217 (0.9%)	217 (0.5%)
04 - Diseases and Disorders of the Respiratory System		189 (0.8%)	189 (0.4%)
01 - Diseases and Disorders of the Nervous System		162 (0.7%)	162 (0.3%)
16 - Diseases and Disorders of Blood, Blood Forming Organs and Immunological Disorders		131 (0.6%)	131 (0.3%)
10 - Endocrine, Nutritional and Metabolic Diseases and Disorders		105 (0.5%)	105 (0.2%)
05 - Diseases and Disorders of the Circulatory System		97 (0.4%)	97 (0.2%)
03 - Ear, Nose, Mouth, Throat, and Craniofacial Diseases and Disorders		84 (0.4%)	84 (0.2%)
21 - Poisonings, Toxic Effects, Other Injuries and Other Complications of Treatment		82 (0.4%)	82 (0.2%)
18 - Infectious and Parasitic Diseases, Systemic or Unspecified Sites		60 (0.3%)	60 (0.1%)
19 - Mental Diseases and Disorders		32 (0.1%)	32 (0.1%)
20 - Alcohol/Drug Use and Alcohol/Drug Induced Organic Mental Disorders		17 (0.1%)	17 (0%)
SS		13 (0.1%)	13 (0%)



Medical Diagnostic Category (MDC)	Principal diagnosis N (%)	Secondary diagnosis N (%)	Total N (%)
02 - Diseases and Disorders of the Eye		10 (0%)	10 (0%)
PP		7 (0%)	7 (0%)
24 - Human Immunodeficiency Virus (HIV) Infections		3 (0%)	3 (0%)
25 - Multiple Significant Trauma		1 (0%)	1 (0%)
Total	23 856 (100%)	23 048 (100%)	46 904 (100%)

SS: Belgian exception = APR-DRG 'MMM' for one-day clinic; PP: pre-MDC (transplants & tracheostomies)

For the hospital stays with endometriosis as principal diagnosis, the most frequent All Patient Refined Diagnosis Related group (APR-DRG, cf. Box 5; Table 21) was by far the surgical group 513, 'Uterine & adnexa procedures for non-malignancy except leiomyoma' (72.9%), followed by the medical 532 'Menstrual & other female reproductive system disorders' (6.7%).

Table 21 – Classification of endometriosis-related hospital admissions with endometriosis as principal diagnosis, All Patient Refined Diagnostic Related groups (APR-DRG)

Medical Diagnostic Category (MDC)	All Patient Refined Diagnostic Related group (APR-DRG)	N (%)
13 - Diseases and Disorders of the Female Reproductive System		2 2129 (92.8%)
	513 Uterine & adnexa procedures for non-malignancy except leiomyoma	17386 (72.9%)
	532 Menstrual & other female reproductive system disorders	1592 (6.7%)
	518 Other female reproductive system & related procedures	1587 (6.7%)
	517 Dilation & curettage for non-obstetric diagnoses	1431 (6.0%)
	514 Female reproductive system reconstructive procedures	112 (0.5%)



Medical Diagnostic Category (MDC)	All Patient Refined Diagnostic Related group (APR-DRG)	N (%)
	510 Pelvic evisceration, radical hysterectomy & other radical gynaecological procedures	21 (0.1%)
06 - Diseases and Disorders of the Digestive System		1002 (4.2%)
	221 Major small & large bowel procedures	773 (3.2%)
	254 Other digestive system diagnoses	103 (0.4%)
	225 Appendectomy	39 (0.2%)
	229 Other digestive system & abdominal procedures	36 (0.2%)
	224 Peritoneal adhesiolysis	29 (0.1%)
	223 Other small & large bowel procedures	12 (0.1%)
	226 Anal procedures	8 (0%)
	227 Hernia procedures except inguinal, femoral & umbilical	2 (0%)
09 - Diseases and Disorders of the Skin, Subcutaneous Tissue and Breast		385 (1.6%)
	385 Other skin, subcutaneous tissue & breast disorders	178 (0.7%)
	361 Skin graft for skin & subcutaneous tissue diagnoses	106 (0.4%)
	364 Other skin, subcutaneous tissue & related procedures	101 (0.4%)

Medical Diagnostic Category (MDC)	All Patient Refined Diagnostic Related group (APR-DRG)	N (%)
00 - Residual Group		340 (1.4%)
	952 Nonextensive procedure unrelated to principal diagnosis	134 (0.6%)
	951 Moderately extensive procedure unrelated to principal diagnosis	119 (0.5%)
	950 Extensive procedure unrelated to principal diagnosis	87 (0.4%)
Total		23 856 (100%)

For those stays with endometriosis recorded as secondary diagnosis, the most frequently assigned principal diagnoses were 'Leiomyoma of the uterus' (D25, 22.5%), 'Encounter for procreative management' (Z31, 10.6%) and 'Polyp of female genital tract' (N84, 6.2%; Table 22).

Table 22 – Principal diagnosis (first 3 digits of ICD-10-BE code) of hospital admissions with endometriosis as secondary diagnosis

Principal diagnosis (first 3 digits)	N (%)
D25 - Leiomyoma of uterus	5184 (22.5%)
Z31 - Encounter for procreative management	2450 (10.6%)
N84 - Polyp of female genital tract	1420 (6.2%)
N81 - Female genital prolapse	1017 (4.4%)
N92 - Excessive, frequent and irregular menstruation	1010 (4.4%)
N97 - Female infertility	984 (4.3%)
N83 - Noninflammatory disorders of ovary, fallopian tube and broad ligament	947 (4.1%)



Principal diagnosis (first 3 digits)	N (%)
D27 - Benign neoplasm of ovary	634 (2.8%)
N85 - Other noninflammatory disorders of uterus, except cervix	548 (2.4%)
C54 - Malignant neoplasm of corpus uteri	355 (1.5%)
N70 - Salpingitis and oophoritis	322 (1.4%)
N94 - Pain and other conditions associated with female genital organs and menstrual cycle	316 (1.4%)
C56 - Malignant neoplasm of ovary	311 (1.4%)
Z30 - Encounter for contraceptive management	301 (1.3%)
D06 - Carcinoma in situ of cervix uteri	296 (1.3%)
N87 - Dysplasia of cervix uteri	283 (1.2%)
Z51 - Encounter for other aftercare	267 (1.2%)
K35 - Acute appendicitis	238 (1.0%)

Principal diagnosis (first 3 digits)	N (%)
N73 - Other female pelvic inflammatory diseases	234 (1.0%)
O00 - Ectopic pregnancy	183 (0.8%)
R10 - Abdominal and pelvic pain	176 (0.8%)
D26 - Other benign neoplasms of uterus	162 (0.7%)
N95 - Menopausal and other perimenopausal disorders	152 (0.7%)
K80 - Cholelithiasis	141 (0.6%)
Q51 - Congenital malformations of uterus and cervix	132 (0.6%)
N72 - Inflammatory disease of cervix uteri	131 (0.6%)
C53 - Malignant neoplasm of cervix uteri	115 (0.5%)
Z40 - Encounter for prophylactic surgery	112 (0.5%)
Other principal diagnoses	4 627 (20.1%)

Table 23 – Number of endometriosis-related hospital admissions in 2016 – 2020 with N80 as principal diagnosis, by age group

5-year group (year)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
00-04	1 (0.0%)	1 (0.0%)				2 (0.0%)
05-09	.	.	.	.	.	.(0%)
10-14	1 (0.0%)	1 (0.0%)	2 (0.0%)	4 (0.1%)	1 (0.0%)	9 (0.0%)
15-19	39 (0.8%)	39 (0.8%)	21 (0.4%)	45 (0.9%)	36 (0.9%)	180 (0.8%)
20-24	209 (4.2%)	264 (5.3%)	198 (4.2%)	271 (5.4%)	240 (5.8%)	1 182 (5.0%)
25-29	725 (14.6%)	697 (13.9%)	631 (13.4%)	682 (13.5%)	588 (14.2%)	3 323 (13.9%)
30-34	839 (16.9%)	904 (18.1%)	820 (17.4%)	890 (17.6%)	824 (19.9%)	4 277 (17.9%)



5-year group (year)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
35-39	805 (16.3%)	861 (17.2%)	785 (16.6%)	874 (17.3%)	659 (15.9%)	3 984 (16.7%)
40-44	851 (17.2%)	834 (16.7%)	784 (16.6%)	857 (17.0%)	654 (15.8%)	3 980 (16.7%)
45-49	758 (15.3%)	763 (15.3%)	812 (17.2%)	729 (14.4%)	578 (13.9%)	3 640 (15.3%)
50-54	431 (8.7%)	382 (7.6%)	400 (8.5%)	422 (8.4%)	351 (8.5%)	1 986 (8.3%)
55-59	153 (3.1%)	132 (2.6%)	126 (2.7%)	141 (2.8%)	95 (2.3%)	647 (2.7%)
60-64	60 (1.2%)	48 (1.0%)	55 (1.2%)	55 (1.1%)	45 (1.1%)	263 (1.1%)
65-69	37 (0.7%)	41 (0.8%)	40 (0.8%)	33 (0.7%)	31 (0.7%)	182 (0.8%)
70-74	23 (0.5%)	19 (0.4%)	21 (0.4%)	28 (0.6%)	26 (0.6%)	117 (0.5%)
75-79	13 (0.3%)	6 (0.1%)	8 (0.2%)	10 (0.2%)	7 (0.2%)	44 (0.2%)
80-84	4 (0.1%)	2 (0.0%)	8 (0.2%)	5 (0.1%)	6 (0.1%)	25 (0.1%)
85+	2 (0.0%)	3 (0.1%)	4 (0.1%)	1 (0.0%)	5 (0.1%)	15 (0.1%)
Total	4 951 (100%)	4 715 (100%)	4 997 (100%)	5 047 (100%)	4 146 (100%)	23 856 (100%)

Table 24 – Number of endometriosis-related hospital admissions in 2016 – 2020 with N80 as secondary diagnosis, by age group

5-year group (year)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
00-04	.	.	.	.	.	.(0%)
05-09	.	.	.	.	.	.(0%)
10-14			1 (0.0%)	11 (0.2%)	2 (0.1%)	14 (0.1%)
15-19	17 (0.4%)	17 (0.4%)	21 (0.4%)	30 (0.6%)	28 (0.7%)	113 (0.5%)
20-24	106 (2.2%)	94 (2.0%)	112 (2.4%)	121 (2.4%)	96 (2.4%)	529 (2.3%)
25-29	371 (7.9%)	380 (8.2%)	427 (9.1%)	405 (8.0%)	359 (9.1%)	1 942 (8.4%)
30-34	585 (12.4%)	542 (11.7%)	621 (13.3%)	709 (14.1%)	616 (15.6%)	3 073 (13.3%)



5-year group (year)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
35-39	608 (12.9%)	575 (12.4%)	587 (12.5%)	703 (13.9%)	499 (12.6%)	2 972 (12.9%)
40-44	642 (13.6%)	723 (15.6%)	714 (15.3%)	677 (13.4%)	595 (15.1%)	3 351 (14.5%)
45-49	850 (18.0%)	783 (16.8%)	783 (16.7%)	822 (16.3%)	590 (14.9%)	3 828 (16.6%)
50-54	597 (12.6%)	639 (13.7%)	553 (11.8%)	606 (12.0%)	471 (11.9%)	2 866 (12.4%)
55-59	341 (7.2%)	289 (6.2%)	334 (7.1%)	346 (6.9%)	237 (6.0%)	1 547 (6.7%)
60-64	199 (4.2%)	199 (4.3%)	174 (3.7%)	195 (3.9%)	161 (4.1%)	928 (4.0%)
65-69	180 (3.8%)	164 (3.5%)	130 (2.8%)	149 (3.0%)	124 (3.1%)	747 (3.2%)
70-74	126 (2.7%)	125 (2.7%)	111 (2.4%)	135 (2.7%)	94 (2.4%)	591 (2.6%)
75-79	59 (1.2%)	62 (1.3%)	68 (1.5%)	70 (1.4%)	49 (1.2%)	308 (1.3%)
80-84	25 (0.5%)	31 (0.7%)	33 (0.7%)	47 (0.9%)	21 (0.5%)	157 (0.7%)
85+	17 (0.4%)	25 (0.5%)	11 (0.2%)	20 (0.4%)	9 (0.2%)	82 (0.4%)
Total	4 723 (100%)	4 648 (100%)	4 680 (100%)	5 046 (100%)	3 951 (100%)	23 048 (100%)

Table 25 – Rate of endometriosis-related hospital admissions per 100 000 women in 2016 – 2020, by age group

5-year group (year)	2016	2017	2018	2019	2020	Total
00-04	0.3	.	0.3	.	.	0.1
05-09	.	.	.	.	.	.
10-14	0.3	0.6	0.6	4.7	0.9	1.5
15-19	18.2	12.4	19.6	24.3	20.7	19.0
20-24	93.6	87.8	114.0	119.2	102.0	103.2
25-29	299.9	273.9	303.1	293.9	258.5	285.9



5-year group (year)	2016	2017	2018	2019	2020	Total
30-34	392.9	375.4	417.3	432.2	383.8	400.4
35-39	383.1	365.3	387.4	421.3	310.0	373.4
40-44	407.1	415.8	428.0	421.2	337.9	401.8
45-49	413.9	411.6	401.1	406.5	310.7	389.2
50-54	253.7	258.1	234.5	261.3	211.3	243.9
55-59	128.3	106.5	118.5	122.6	83.1	111.7
60-64	75.0	72.3	62.2	68.8	55.8	66.7
65-69	68.9	64.8	54.1	57.0	47.9	58.5
70-74	60.9	55.6	47.1	57.1	41.0	52.0
75-79	33.3	33.4	35.8	38.6	26.6	33.5
80-84	15.2	20.7	18.7	27.6	14.4	19.3
85+	9.1	13.5	6.4	9.5	6.3	8.9
Total	168.5	162.4	167.1	173.5	138.7	162.0

The denominators of each rate is the mid-year Belgian female population in the age group (i.e. average of the number of women on the first January of year Y and year Y+1, downloaded from www.statbel.be).

Table 26 – ICD-10-BE codes registered for hospital admissions with endometriosis as principal diagnosis

Principal diagnosis	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
N80.0 Endometriosis of uterus	2 072 (41.9%)	2 054 (43.6%)	1 991 (39.8%)	1 997 (39.6%)	1 621 (39.1%)	9 735 (40.8%)
N80.1 Endometriosis of ovary	1 148 (23.2%)	1 089 (23.1%)	1 256 (25.1%)	1 211 (24.0%)	959 (23.1%)	5 663 (23.7%)
N80.2 Endometriosis of fallopian tube	88 (1.8%)	86 (1.8%)	90 (1.8%)	111 (2.2%)	79 (1.9%)	454 (1.9%)



Principal diagnosis	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
N80.3 Endometriosis of pelvic peritoneum	843 (17.0%)	748 (15.9%)	870 (17.4%)	902 (17.9%)	791 (19.1%)	4 154 (17.4%)
N80.4 Endometriosis of rectovaginal septum and vagina	261 (5.3%)	237 (5.0%)	241 (4.8%)	247 (4.9%)	204 (4.9%)	1 190 (5.0%)
N80.5 Endometriosis of intestine	185 (3.7%)	190 (4.0%)	203 (4.1%)	248 (4.9%)	188 (4.5%)	1 014 (4.3%)
N80.6 Endometriosis in cutaneous scar	86 (1.7%)	77 (1.6%)	90 (1.8%)	86 (1.7%)	59 (1.4%)	398 (1.7%)
N80.8 Other endometriosis (incl. Endometriosis of thorax)	154 (3.1%)	153 (3.2%)	173 (3.5%)	174 (3.5%)	168 (4.0%)	822 (3.5%)
N80.9 Endometriosis, unspecified	114 (2.3%)	81 (1.7%)	83 (1.7%)	71 (1.4%)	77 (1.9%)	426 (1.8%)
Total	4 951 (100%)	4 715 (100%)	4 997 (100%)	5 047 (100%)	4 146 (100%)	23 856 (100%)

Table 27 – ICD-10-BE codes registered for hospital admissions with endometriosis as secondary diagnosis

Secondary Diagnosis	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
N80.0 Endometriosis of uterus	2 645 (56.0%)	2 548 (54.8%)	2 473 (52.8%)	2 671 (52.9%)	1 927 (48.8%)	12 264 (53.2%)
N80.1 Endometriosis of ovary	686 (14.5%)	667 (14.4%)	658 (14.1%)	634 (12.6%)	511 (12.9%)	3 156 (13.7%)
N80.2 Endometriosis of fallopian tube	150 (3.2%)	157 (3.4%)	134 (2.9%)	209 (4.1%)	149 (3.8%)	799 (3.5%)
N80.3 Endometriosis of pelvic peritoneum	993 (21.0%)	886 (19.1%)	919 (19.6%)	988 (19.6%)	797 (20.2%)	4 583 (19.9%)
N80.4 Endometriosis of rectovaginal septum and vagina	78 (1.7%)	56 (1.2%)	73 (1.6%)	88 (1.7%)	69 (1.7%)	364 (1.6%)
N80.5 Endometriosis of intestine	114 (2.4%)	109 (2.3%)	93 (2.0%)	94 (1.9%)	107 (2.7%)	517 (2.2%)



Secondary Diagnosis	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)	2020 N (%)	Total N (%)
N80.6 Endometriosis in cutaneous scar	10 (0.2%)	12 (0.3%)	14 (0.3%)	11 (0.2%)	17 (0.4%)	64 (0.3%)
N80.8 Other endometriosis (incl. Endometriosis of thorax)	217 (4.6%)	253 (5.4%)	221 (4.7%)	226 (4.5%)	198 (5.0%)	1 115 (4.8%)
N80.9 Endometriosis, unspecified	386 (8.2%)	491 (10.6%)	608 (13.0%)	727 (14.4%)	642 (16.2%)	2 854 (12.4%)
Total	4 723 (100%)	4 648 (100%)	4 680 (100%)	5 046 (100%)	3 951 (100%)	23 048 (100%)

Table 28 – Most commonly recorded surgical procedures when endometriosis was the principal or secondary diagnosis

Rank	Most common procedures when endometriosis was the principal diagnosis (code; proportion)	Most common procedures when endometriosis was one of the secondary diagnoses (code; proportion)
1	Ovarian cystectomy with or without ovarioplasty, with anatomopathological confirmation (432596 - 432600; 18.4%)	Total hysterectomy by laparoscopic route, with anatomopathological confirmation (432736 - 432740; 21.7%)
2	Diagnostic hysteroscopy with or without biopsy or cytology, with protocol (432390 - 432401; 17.5%)	Diagnostic hysteroscopy with or without biopsy or cytology, with protocol (432390 - 432401; 13.0%)
3	Total hysterectomy by laparoscopic route, with anatomopathological confirmation (432736 - 432740; 15.7%)	Total hysterectomy, by vaginal route, including anterior colporrhaphy and/or possible posterior colpoperineorrhaphy (431314 - 431325; 11.8%)
4	Exeresis of tumours of the retroperitoneal tissue (243751 - 243762; 12.5%)	Laparoscopically assisted vaginal hysterectomy, including the vaginal removal, with anatomopathological confirmation (432670 - 432681; 8.7%)
5	Ovarioplasty or myomectomy (myoma less than 2 cm in diameter) or treatment of endometriosis with anatomopathological confirmation (432530 - 432541; 8.7%)	Total hysterectomy, by abdominal route (431270 - 431281; 8.6%)
6	Unilateral or bilateral salpingectomy or ovariectomy or adnexectomy with anatomopathological confirmation (432633 - 432644; 7.4%)	Ovarian cystectomy with or without ovarioplasty, with anatomopathological confirmation (432596 - 432600; 8.5%)
7	Laparoscopically assisted vaginal hysterectomy, including the vaginal removal, with anatomopathological confirmation (432670 - 432681; 6.4%)	Ovarian plastic surgery or myomectomy (myoma less than 2 cm in diameter) or treatment of endometriosis with anatomopathological confirmation (432530 - 432541; 7.1%)



Rank	Most common procedures when endometriosis was the principal diagnosis (code; proportion)	Most common procedures when endometriosis was one of the secondary diagnoses (code; proportion)
8	Total hysterectomy, by vaginal route, including anterior colporrhaphy and/or possible posterior colpoperineorrhaphy (431314 - 431325; 6.3%)	Unilateral or bilateral salpingectomy or ovariectomy or adnexectomy with anatomopathological confirmation (432633 - 432644; 6.7%)
9	Cystoscopy, with placement of a ureteral catheter (260293 - 260304; 4.8%)	Subtotal hysterectomy with anatomopathological confirmation (432655 - 432666; 2.5%)
10	Radical treatment due to pelvic endometriosis* (431211 - 431222; 3.7%)	Laparoscopy for intervention on the tubae, including the pneumoperitoneum (432692 - 432703; 2.4%)

*: The code for 'Radical treatment due to pelvic endometriosis' (431211-431222) was dropped on 31 May 2017, which may explain the low frequency.

Table 29 – Number of hospital admissions with endometriosis as principal diagnosis and a surgical intervention in 2016-2020, by sub-article of the fee schedule involved during the admission

Surgery	year					
	2016	2017	2018	2019	2020	Total
Total number of stays (100%)	3 926	3 714	4 044	4 052	3 343	19 079 (*)
Urologic surgery (art. 14 j)	253 (6.4%)	244 (6.6%)	259 (6.4%)	252 (6.2%)	219 (6.6%)	1 227 (6.4%)
Gynaecologic surgery (art. 14 g)	3 594 (91.5%)	3 301 (88.9%)	3 504 (86.6%)	3 532 (87.2%)	2 850 (85.3%)	16 781 (88.0%)
Abdominal surgery (art. 14 d)	517 (13.2%)	626 (16.9%)	805 (19.9%)	863 (21.3%)	741 (22.2%)	3 552 (18.6%)
Thoracic surgery (art. 14 e)	10 (0.3%)	5 (0.1%)	12 (0.3%)	7 (0.2%)	13 (0.4%)	47 (0.2%)

(*) The linkage of the 23 856 admissions with endometriosis as principal diagnosis was successful in 22 839 hospital admissions (96.3%, reflecting approximately 3.6% of women not covered by the compulsory health care insurance and 0.1% data flaws) and a surgical intervention was billed in 19 079 of them.

Note: the row totals exceed 100%, as patients may have undergone different types of surgical interventions.



Table 30 – Surgical readmissions after a stay in hospital with endometriosis as principal diagnosis and during which a surgical procedure for endometriosis was recorded, 2016 - 2020

Index year	2016	2017	2018	2019	2020	TOTAL
Number of readmissions	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
0	3 268 (85.8%)	3 027 (87.9%)	3 317 (90.0%)	3 385 (93.2%)	2 852 (96.2%)	15 849 (90.4%)
1	445 (11.7%)	356 (10.3%)	330 (9.0%)	231 (6.4%)	109 (3.7%)	1 471 (8.4%)
2	87 (2.3%)	47 (1.4%)	32 (0.9%)	16 (0.4%)	3 (0.1%)	185 (1.1%)
3	7 (0.2%)	10 (0.3%)	2 (0.1%)	0	0	19 (0.1%)
4+ (max 11)	3 (0.1%)	2 (0.1%)	3 (0.1%)	0	0	8 (0.0%)
Total	3 810 (100%)	3 442 (100%)	3 684 (100%)	3 632 (100%)	2 964 (100%)	17 532 (100%)



Table 31 – Principal diagnosis (first 4 digits of ICD-10-BE code) of readmissions within 30 days after a stay in hospital with endometriosis as principal diagnosis and during which a surgical procedure for endometriosis was recorded, 2016 - 2020

Principal diagnosis (first 4 digits)
N801 - Endometriosis of ovary
N803 - Endometriosis of pelvic peritoneum
N800 - Endometriosis of uterus
N805 - Endometriosis of intestine
Z466 - Encounter for fitting and adjustment of urinary device
N808 - Other endometriosis
G891 - Acute pain, not elsewhere classified
N10 - Acute pyelonephritis
N804 - Endometriosis of rectovaginal septum and vagina
N998 - Other intraoperative and postprocedural complications and disorders of genitourinary system
K918 - Other intraoperative and postprocedural complications and disorders of digestive system
R310 - Gross haematuria
T813 - Disruption of wound, not elsewhere classified
T814 - Infection following a procedure
Z488 - Encounter for other specified postprocedural aftercare
A09 - Infectious gastroenteritis and colitis, unspecified
I824 - Acute embolism and thrombosis of deep veins of lower extremity
K353 - Acute appendicitis with localized peritonitis

Principal diagnosis (first 4 digits)

K358 - Other and unspecified acute appendicitis
K37 - Unspecified appendicitis
K528 - Other specified noninfective gastroenteritis and colitis
K660 - Peritoneal adhesions (postprocedural) (post infection)
K913 - Postprocedural intestinal obstruction
N131 - Hydronephrosis with ureteral stricture, not elsewhere classified
N133 - Other and unspecified hydronephrosis
N209 - Urinary calculus, unspecified
N300 - Acute cystitis
N701 - Chronic salpingitis and oophoritis
N733 - Female acute pelvic peritonitis
N739 - Female pelvic inflammatory disease, unspecified
N809 - Endometriosis, unspecified
N832 - Other and unspecified ovarian cysts
N858 - Other specified noninflammatory disorders of uterus
N921 - Excessive and frequent menstruation with irregular cycle
N948 - Other specified conditions associated with female genital organs and menstrual cycle
N997 - Accidental puncture and laceration of a genitourinary system organ or structure during a procedure
R109 - Unspecified abdominal pain
T818 - Other complications of procedures, not elsewhere classified



Appendix 3.2. Results at the hospital level

Table 32 – Distribution of endometriosis-related hospital admissions* among Belgian hospitals

Index year	2016	2017	2018	2019	2020	Average per year 2016 - 2020	Total 2016-2020
Total number of stays	9 672	9 363	9 672	10 093	8 096	9 379.2	46 896
Minimum	1	1	2	3	3	2.6	13
Q1	30	33	30	29	25	30	150
Median	63	60	57	59	44	54.6	273
Q3	112	117	116	130	91	122.2	611
Maximum	684	682	766	860	597	486.8	2 434

*: Both endometriosis as principal diagnosis as well as endometriosis as one of the secondary diagnosi(e)s are considered; five (geriatric or rehabilitation) hospitals which recorded each no more than three endometriosis-related stays during 2016-2020 were not included in the hospital level analysis (total excluded stays n=8).



Figure 12 – Distribution of endometriosis-related hospital admissions among Belgian hospitals, by type of diagnosis (2016-2020)

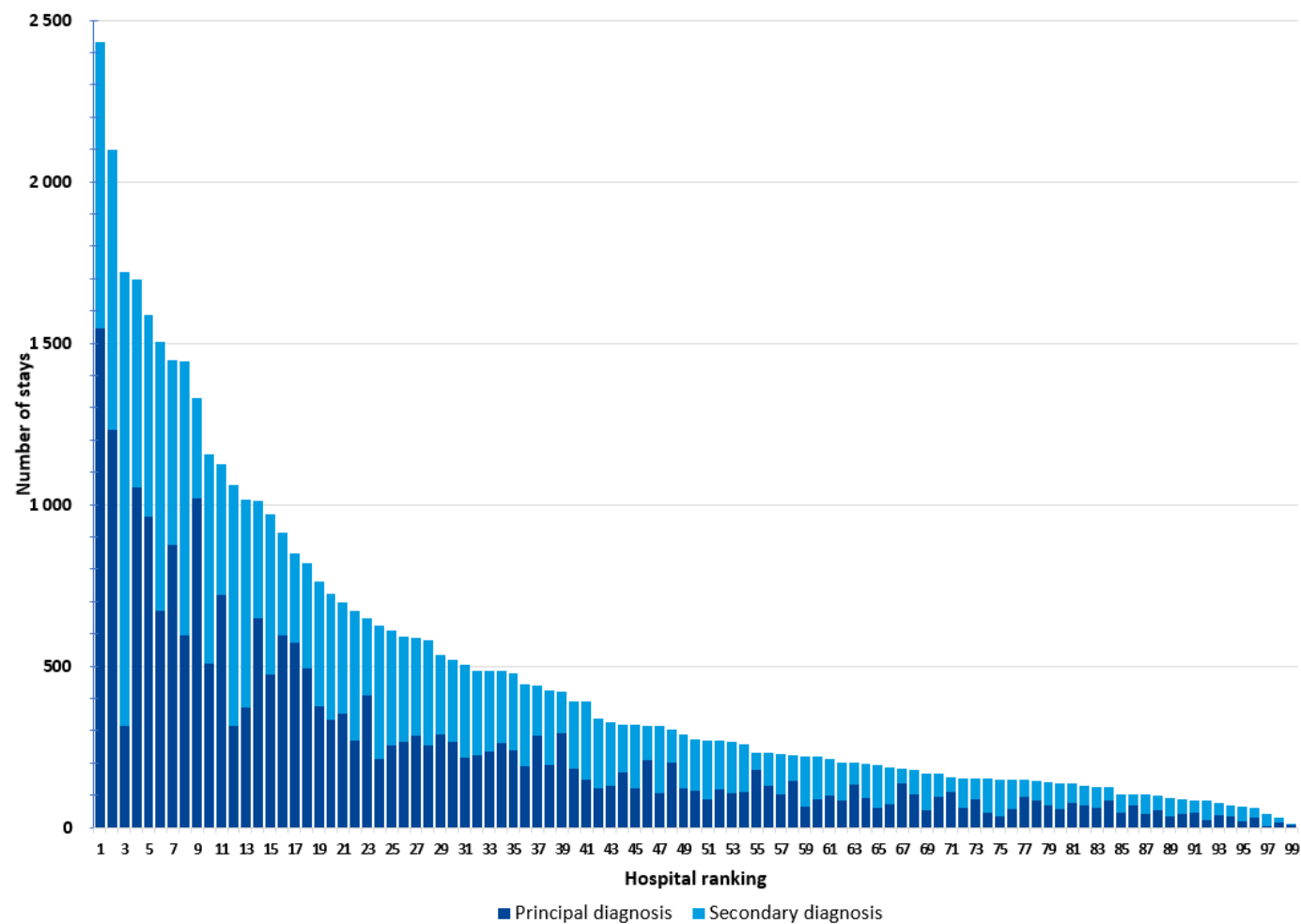


**Table 33 – Distribution of endometriosis-related hospital admissions* among Belgian hospitals per year, by hospital type**

Type of hospital	General N=75	University like ^s N=17	University N=7
Total number of stays per year	5 720.4	2 215.2	1 443.6
Mean (SD)	76.3 (85.1)	130.3 (97.4)	206.2 (125.6)
Minimum	2.6	5.8	97.4
Q1	28.2	54	106.8
Median	44.8	83.8	152.2
Q3	96.8	202.2	339.6
Maximum	486.8	300.6	419.8

*: Both endometriosis as principal diagnosis as well as endometriosis as one of the secondary diagnosi(e)s are considered; ^s: University like hospitals: acute hospitals without a medical school that are allocated a number of university beds.



APPENDIX 4. SURVEY IN THE BELGIAN HOSPITALS

Appendix 4.1. Dutch version of the online survey

Appendix 4.1.1. Introductory text

Geachte dokter,

Het onderzoeksteam van het KCE dankt u voor uw interesse tot deelname aan deze studie.

In het KCE rapport zal de lijst worden opgenomen van die ziekenhuizen die in deze vragenlijst aangeven een endometriosekliniek te hebben opgericht. Met andere woorden, de antwoorden op de vragen “In welk ziekenhuis werkt u?” en “Heeft uw ziekenhuis op dit ogenblik een of meerdere campus(sen) met een endometriosekliniek (endometriose expertisecentrum)?” zullen niet anoniem worden weergegeven in het rapport. Voor de andere vragen wordt de anonimiteit van de deelnemende ziekenhuizen verzekerd. Door deel te nemen aan deze vragenlijst, gaan we ervan uit dat u hiermee akkoord gaat.

De vragenlijst kan zowel via computer als tablet of smartphone ingevuld worden.

Het invullen van de vragenlijst duurt ongeveer 15 minuten. We vragen u met aandrang om het invullen van de vragenlijst niet te onderbreken, want dat geeft problemen met de software.

U kan teruggaan door te klikken op de knop “Vorige”. We raden je af om het pijltje “Vorige” van je browser te gebruiken want dan raak je al je antwoorden kwijt.

U kan voor vragen of technische problemen contact opnemen met xx (x.x@kce.fgov.be).



Appendix 4.1.2. Questionnaire

S1 - Algemene informatie

*: vragen verplicht in te vullen

Code	Vraag	Antwoorden	Commentaar
S1Q1*	In welk ziekenhuis werkt u? <i>Als u in meer dan 1 ziekenhuis werkt, dan vragen we u vriendelijk om het ziekenhuis aan te duiden met het emailadres van ontvangst van de enquête. (Om het zoeken te faciliteren, werden de namen van de ziekenhuizen in de drop-down lijst alfabetisch gerangschikt. Naast de naam vindt u ook het erkenningsnummer.)</i>	Kies het erkenningsnummer van uw ziekenhuis	1 antwoord Drop-down menu met lijst erkenningsnummers
S1Q2*	Wat is (zijn) uw functie(s) binnen het ziekenhuis?	○ Hoofd endometrisekliniek ○ Diensthoofd gynaecologie ○ Gynaecoloog met expertise in endometriose ○ Gynaecoloog ○ Hoofdarts ○ Andere	Meerdere antwoorden mogelijk
S1Q2 b is	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S1Q3*	Heeft uw ziekenhuis op dit ogenblik een of meerdere campus(sen) met een endometrisekliniek (expertisecentrum voor endometriose)? <i>Endometriseklinieken of expertisecentra voor endometriose zijn in België niet officieel erkend en er zijn bijgevolg geen officiële erkenningscriteria. Toch zijn er verschillende ziekenhuizen die, naar analogie van bv. voorbeelden uit het binnen- en buitenland, endometriseklinieken hebben opgericht.</i>	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord Indien antwoord ○ Ja > ga naar vraag S1Q4 ○ Neen > ga naar vraag S3Q1



Code	Vraag	Antwoorden	Commentaar
	<i>In deze enquête verwijzen we naar deze initiatieven wanneer we het hebben over endometrioseklinieken.</i>		Ik weet het niet > ga naar vraag S3Q1
S1Q4*	Kan u voor uw ziekenhuis de campus(sen) selecteren die een endometriosekliniek heeft (hebben)?	Kies de campus(sen)	Meerdere antwoorden mogelijk Drop-down menu met lijst erkenningsnummers EN voorzie optie "Ik weet het niet" Ga naar vraag S2Q1

S2 - Organisatie en werking van de endometriosekliniek

Code	Vraag	Antwoorden	Commentaar
S2Q1	<i>Wanneer uw ziekenhuis meer dan 1 campus heeft met een endometriosekliniek, vragen we u om in de verdere vragen van de enquête te focussen op de kliniek waarmee u het meest vertrouwd bent en waarover u de meest nauwkeurige informatie kunt verstrekken.</i> In welk jaar werd de endometriosekliniek in uw ziekenhuis opgestart?	Geef het jaar aan waarin de endometriosekliniek in uw ziekenhuis werd opgericht.	1 antwoord Drop-down menu met jaartallen van 1970 tot nu Inclusief optie "ik weet het niet"
S2Q2*	Welke beroepsprofielen maken deel uit van het endometriosis-team van uw ziekenhuis?	- Arts-specialist in de gynaecologie-verloskunde - Arts-specialist in de röntgendiagnose - Arts-specialist in de abdominale heelkunde - Arts-specialist in de thoracale heelkunde	Meerdere antwoorden mogelijk



Code	Vraag	Antwoorden	Commentaar
		○ Arts-specialist in de pathologische anatomie ○ Arts-specialist in de urologie ○ Arts-specialist werkzaam in het pijncentrum ○ Arts-specialist in de fysische geneeskunde en revalidatie ○ Arts-specialist in de psychiatrie ○ Vroedvrouw ○ Vroedvrouw-specialist ○ Verpleegkundige ○ Verpleegkundig-specialist ○ Kinesitherapeut ○ Diëtist ○ Psycholoog ○ Seksuoloog ○ Sociaal werker ○ Andere ○ Ik weet het niet	
S2Q2 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S2Q3*	Maakt een arts-specialist werkzaam in het fertiliteitscentrum deel uit van het endometriosis-team van uw ziekenhuis?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord
S2Q4*	Hoeveel nieuw aangemelde patiënten met het vermoeden/de diagnose van endometriose ziet de endometriosekliniek gemiddeld per maand?	○ <10 ○ 10-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Ik weet het niet	1 antwoord



Code	Vraag	Antwoorden	Commentaar
S2Q5*	Hoe lang bedraagt de gemiddelde wachttijd voor een nieuw aangemelde patiënt een eerste afspraak krijgt op de endometriosekliniek in uw ziekenhuis?	- o < 1 maand - o 1 tot 3 maanden - o 3 tot 6 maanden - o 6 tot 9 maanden - o ≥ 9 maanden - o Ik weet het niet	1 antwoord
S2Q6*	Organiseert de endometriosekliniek in uw ziekenhuis een multidisciplinair endometriose-overleg waar de diagnose en het behandelplan van patiënten met endometriose door een multidisciplinair team besproken worden?	- o Ja - o Neen - o Ik weet het niet	1 antwoord Indien antwoord - o Ja > ga naar vraag S2Q7 - o Neen > ga naar vraag S2Q10 - o Ik weet het niet > ga naar vraag S2Q10
S2Q7*	Welke beroepsprofielen zijn doorgaans aanwezig tijdens het multidisciplinair endometriose-overleg waar de diagnose en het behandelplan van patiënten met endometriose door een multidisciplinair team besproken worden?	- o Arts-specialist in de gynaecologie-verloskunde - o Arts-specialist in de röntgendiagnose - o Arts-specialist in de abdominale heelkunde - o Arts-specialist in de thoracale heelkunde - o Arts-specialist in de pathologische anatomie - o Arts-specialist in de urologie - o Arts-specialist werkzaam in het pijncentrum - o Arts-specialist in de fysische geneeskunde en revalidatie - o Arts-specialist in de psychiatrie - o Vroedvrouw - o Vroedvrouw-specialist	Meerdere antwoorden mogelijk



Code	Vraag	Antwoorden	Commentaar
		○ Verpleegkundige ○ Verpleegkundig-specialist ○ Kinesitherapeut ○ Diëtist ○ Psycholoog ○ Seksuoloog ○ Sociaal werker ○ Andere ○ Ik weet het niet	
S2Q7 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S2Q8*	Is er doorgaans een arts-specialist werkzaam in het fertiliteitscentrum aanwezig tijdens het multidisciplinair endometriose-overleg?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord
S2Q9*	Welke subgroepen van patiënten worden doorgaans besproken op het multidisciplinair endometriose-overleg? <i>Voor de definitie van diepe endometriose wordt verwezen naar de meest recente ESHRE richtlijn (2022, p 53): “Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter.”</i>	○ Alle patiënten met (vermoeden van) endometriose ○ Patiënten met (vermoeden van) endometriose voor wie chirurgie wordt ingepland ○ Patiënten met (vermoeden van) diepe endometriose voor wie chirurgie wordt ingepland ○ Patiënten met (vermoeden van) endometriose en fertiliteitsproblemen ○ Andere ○ Ik weet het niet	Meerdere antwoorden mogelijk
S2Q9 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	



Code	Vraag	Antwoorden	Commentaar
S2Q10 *	Van wie krijgt de endometriosekliniek in uw ziekenhuis op regelmatige basis patiënten met (vermoeden van/een diagnose van) endometriose doorgestuurd ?	○ Artsen werkzaam in ziekenhuizen van hetzelfde locoregionale netwerk ○ Artsen werkzaam in ziekenhuizen die niet tot hetzelfde locoregionale netwerk behoren ○ Artsen-specialisten in de gynaecologie-verloskunde die in een privépraktijk werken ○ Huisartsen ○ CLB-artsen ○ Arbeidsartsen ○ Adviserend artsen (<i>verbonden aan het ziekenfonds, oordelen of iemand voldoet aan de erkenningsvoorwaarden voor arbeidsongeschiktheid om een ziekte-uitkering te krijgen</i>) ○ Controle-artsen (<i>krijgen van een werkgever de opdracht om te controleren of afwezige werknemers gewettigd afwezig zijn</i>) ○ Artsen uit het buitenland ○ Kinesitherapeuten ○ Patiënten die op eigen initiatief komen ○ Andere ○ Ik weet het niet	Meerdere antwoorden mogelijk
S2Q10 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S2Q11 *	Zijn er in de endometriosekliniek van uw ziekenhuis één of meer personeelsleden verantwoordelijk voor de coördinatie en continuïteit van de zorg (vergelijkbaar met de rol van borstverpleegkundigen in	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord Indien antwoord



Code	Vraag	Antwoorden	Commentaar
	borstklinieken)?		○ Ja > ga naar vraag S2Q12 ○ Neen > ga naar vraag S2Q13 ○ Ik weet het niet > ga naar vraag S2Q13
S2Q12 *	Wie staat in de endometriosekliniek van uw ziekenhuis in voor de coördinatie en continuïteit van de zorg?	○ Vroedvrouw ○ Vroedvrouw-specialist ○ Verpleegkundige ○ Verpleegkundig-specialist ○ Gynaecoloog van de endometriosekliniek ○ Andere ○ Ik weet het niet	Meerdere antwoorden mogelijk
S2Q12 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S2Q13 *	Hoeveel operaties owv (vermoeden van) endometriose worden gemiddeld per MAAND uitgevoerd in de endometriosekliniek van uw ziekenhuis?	○ Geen ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Ik weet het niet	1 antwoord
S2Q14 *	Hoeveel operaties owv (vermoeden van) DIEPE endometriose worden gemiddeld per JAAR uitgevoerd in de endometriosekliniek van uw ziekenhuis?	○ Geen ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40	1 antwoord



Code	Vraag	Antwoorden	Commentaar
	<i>Voor de definitie van diepe endometriose wordt verwezen naar de meest recente ESHRE richtlijn (2022, p 53): "Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter."</i>	○ 41-50 ○ >50 ○ Ik weet het niet	
S2Q15 *	Zijn er patiënten met een specifieke vorm van endometriose, die de endometriosekliniek van uw ziekenhuis doorstuurt naar andere Belgische centra met meer (specifieke) expertise in endometriosechirurgie ?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord Indien antwoord ○ Ja > ga naar vraag S2Q16 ○ Neen > ga naar vraag S2Q17 ○ Ik weet het niet > ga naar vraag S2Q17
S2Q16	Welke type patiënten worden vanuit de endometriosekliniek van uw ziekenhuis doorgestuurd naar andere Belgische centra met meer (specifieke) expertise in endometriosechirurgie ?	[open veld]	
S2Q17 *	Worden er vanuit de endometriosekliniek van uw ziekenhuis patiënten doorgestuurd naar centra in het buitenland met meer (specifieke) expertise in endometriosechirurgie?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord Indien antwoord ○ Ja > ga naar vraag S2Q18 ○ Neen > ga naar vraag S4Q1 ○ Ik weet het niet > ga naar vraag S4Q1
S2Q18	Welk type patiënten worden vanuit de endometriosekliniek van uw ziekenhuis doorgestuurd naar andere Belgische centra met meer (specifieke) expertise in endometriosechirurgie?	[open veld]	Ga naar S4Q1

**S3 - Organisatie van endometriosezorg in ziekenhuizen zonder endometriosekliniek**

Code	Vraag	Antwoorden	Commentaar
S3Q1*	Wanneer een patiënt met een vermoeden van endometriose zich meldt in uw ziekenhuis, wordt zij dan gewoonlijk voor de diagnostische onderzoeken en/of diagnostisch advies verwezen naar	○ Een van de gynaecologen van uw ziekenhuis zonder specifieke expertise in endometriose ○ Gynaecoloog in uw ziekenhuis met specifieke expertise in endometriose ○ Een van de radiologen van uw ziekenhuis zonder specifieke expertise in endometriose ○ Radioloog in uw ziekenhuis met specifieke expertise in endometriose ○ Endometriosekliniek binnen hetzelfde locoregionale netwerk ○ Endometriosekliniek buiten hetzelfde locoregionale netwerk ○ Andere, specificeer [open veld] ○ Ik weet het niet	Meerdere antwoorden mogelijk
S3Q1 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]	
S3Q2*	Wordt in uw ziekenhuis een multidisciplinair endometriose-overleg georganiseerd waar de diagnose en het behandelplan van patiënten met endometriose door een multidisciplinair team besproken worden?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord Indien antwoord ○ Ja > ga naar vraag S3Q3 ○ Neen > ga naar vraag S3Q6 ○ Ik weet het niet > ga naar vraag S3Q6



S3Q3*	Welke beroepsprofielen zijn doorgaans aanwezig tijdens het multidisciplinair endometriose-overleg waar de diagnose en het behandelplan van patiënten met endometriose door een multidisciplinair team besproken worden?	○ Arts-specialist in de gynaecologie-verloskunde ○ Arts-specialist in de röntgendiagnose ○ Arts-specialist in de abdominale heelkunde ○ Arts-specialist in de thoracale heelkunde ○ Arts-specialist in de pathologische anatomie ○ Arts-specialist in de urologie ○ Arts-specialist werkzaam in het pijncentrum ○ Arts-specialist in de fysische geneeskunde en revalidatie ○ Arts-specialist in de psychiatrie ○ Vroedvrouw ○ Vroedvrouw-specialist ○ Verpleegkundige ○ Verpleegkundig-specialist ○ Kinesitherapeut ○ Diëtist ○ Psycholoog ○ Seksuoloog ○ Sociaal werker ○ Andere, specificeer ○ Ik weet het niet	Meerdere mogelijk	antwoorden
S3Q3 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]		
S3Q4*	Is er doorgaans een arts-specialist werkzaam in het fertiliteitscentrum aanwezig tijdens het multidisciplinair endometriose-overleg?	○ Ja ○ Neen ○ Ik weet het niet	1 antwoord	



S3Q5*	Welke subgroepen van patiënten worden doorgaans besproken op het multidisciplinair endometriose-overleg ?	- o Alle patiënten met (vermoeden van) endometriose - o Patiënten met (vermoeden van) endometriose voor wie chirurgie wordt ingepland - o Patiënten met (vermoeden van) diepe endometriose voor wie chirurgie wordt ingepland - o Patiënten met (vermoeden van) endometriose en fertiliteitsproblemen - o Andere, specificeer - o Ik weet het niet	Meerdere mogelijk	antwoorden
S3Q5 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]		
S3Q7*	Wanneer bij een patiënt in uw ziekenhuis endometriose vermoed of gediagnosticeerd wordt (met uitzondering van diepe endometriose), wordt zij dan gewoonlijk voor de chirurgie behandeld door/verwezen naar <i>Voor de definitie van diepe endometriose wordt verwezen naar de meest recente ESHRE richtlijn (2022, p 53): “Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter.”</i>	- o Een van de gynaecologen van uw ziekenhuis (zonder specifieke expertise in endometriose) - o Gynaecoloog in uw ziekenhuis met specifieke expertise in endometriosechirurgie - o Algemeen chirurg in uw ziekenhuis met specifieke expertise in endometriosechirurgie - o Endometriosekliniek binnen hetzelfde locoregionale netwerk - o Endometriosekliniek buiten hetzelfde locoregionale netwerk - o Endometriosekliniek in het buitenland - o Andere - o Ik weet het niet	Meerdere mogelijk	antwoorden



S3Q7 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	o [open veld]		
S3Q8*	Wanneer bij een patiënt in uw ziekenhuis diepe endometriose vermoed of gediagnosticeerd wordt, wordt zij dan gewoonlijk voor de chirurgie behandeld door/verwezen naar <i>Voor de definitie van diepe endometriose wordt verwezen naar de meest recente ESHRE richtlijn (2022, p 53): "Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter."</i>	- o Een van de gynaecologen van uw ziekenhuis (zonder specifieke expertise in endometriose) - o Gynaecoloog in uw ziekenhuis met specifieke expertise in endometriosechirurgie - o Algemeen chirurg in uw ziekenhuis met specifieke expertise in endometriosechirurgie - o Endometriosekliniek binnen hetzelfde locoregionale netwerk - o Endometriosekliniek buiten hetzelfde locoregionale netwerk - o Endometriosekliniek in het buitenland - o Andere - o Ik weet het niet	Meerdere mogelijk	antwoorden
S3Q8 bis	U hebt op de vorige vraag 'Andere' geantwoord. Kan U dit antwoord specificeren?	[open veld]		
S3Q9*	Hoeveel operaties owv (vermoeden van) endometriose worden gemiddeld per MAAND uitgevoerd in uw ziekenhuis?	- o Geen - o 1-5 - o 6-10 - o 11-20 - o 21-30 - o 31-40 - o 41-50 - o >50 - o Ik weet het niet	1 antwoord	



S3Q10 *	Hoeveel operaties owv (vermoeden van) DIEPE endometriose worden gemiddeld per JAAR uitgevoerd in uw ziekenhuis? <i>Voor de definitie van diepe endometriose wordt verwezen naar de meest recente ESHRE richtlijn (2022, p 53): "Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter."</i>	- o Geen - o 1-5 - o 6-10 - o 11-20 - o 21-30 - o 31-40 - o 41-50 - o >50 - o Ik weet het niet	1 antwoord
S3Q11 *	Hoe tevreden bent u dusver over de samenwerking met de endometriosekliniek(en) waarnaar u doorverwijst?	- o Heel tevreden - o Tevreden - o Ontevreden - o Heel ontevreden - o Ik weet het niet - o Ik verwijs geen patiënten naar een endometriosekliniek	1 antwoord
S3Q12	Kan u uw antwoord op vorige vraag verder toelichten?	[open veld]	
S3Q13 *	Zijn er plannen om in de nabije toekomst binnen uw ziekenhuis een multidisciplinaire endometriosekliniek op te richten?	- o Ja - o Neen - o Ik weet het niet	1 antwoord Ga naar S4Q1

S4 – Endometriosezorg verbeteren

Code	Vraag	Antwoorden	Commentaar
S4Q1	Hoe kan volgens u de zorg voor patiënten met endometriose binnen uw ziekenhuis verder verbeterd worden?	[open veld]	
S4Q2	Hoe kan volgens u de zorg voor patiënten met endometriose in het algemeen (dus ook buiten uw ziekenhuis) verder verbeterd worden?	[open veld]	Ga naar S5Q1

**S5 - Aanvullende opmerkingen**

Code	Vraag	Antwoorden	Commentaar
S5Q1	Wilt u nog aanvullende opmerkingen maken over de inhoud van deze enquête of de KCE-studie over endometriose?	[open veld]	

Hartelijk dank dat u de tijd heeft genomen om deze enquête in te vullen. Mocht u nog vragen hebben, aarzel dan niet om contact op te nemen met xx (x.x@kce.fgov.be).



Appendix 4.2. French version of the online survey

Appendix 4.2.1. Introductory text

Cher Docteur,

L'équipe de recherche du KCE vous remercie pour votre intérêt à participer à cette étude.

La liste des hôpitaux ayant déclaré dans ce questionnaire qu'ils disposaient d'une clinique de l'endométriose sera publiée dans le rapport du KCE. En d'autres termes, les réponses aux questions « Dans quel hôpital travaillez-vous ? » et « Votre hôpital a-t-il actuellement un ou plusieurs site(s) disposant d'une clinique de l'endométriose (centre d'expertise de l'endométriose) ? » ne seront pas rapportées de façon anonymisée dans le rapport. Pour les autres questions, l'anonymat des hôpitaux participants est garanti. En participant à ce questionnaire, nous supposons que vous êtes d'accord avec ce qui précède.

L'enquête peut être complétée sur un ordinateur, une tablette ou un smartphone.

Répondre à l'enquête vous prendra environ 15 minutes. Nous vous invitons à ne pas vous interrompre lorsque vous complétez le questionnaire, car cela entraînerait des problèmes avec le logiciel.

Vous pouvez également revenir en arrière en cliquant sur « précédent ». Nous vous déconseillons d'utiliser la flèche de retour en arrière de votre navigateur. Ceci vous ferait perdre l'ensemble de vos réponses.

Une fois le questionnaire finalisé, il ne sera plus possible de modifier vos réponses.

Pour toute question ou problème technique, vous pouvez contacter xx (x.x@kce.fgov.be).



Appendix 4.2.2. Questionnaire

S1 - Informations générales

*: champs obligatoires

Code	Question	Réponses	Commentaire
S1Q1*	Dans quel hôpital travaillez-vous ? <i>Si vous travaillez dans plus d'un hôpital, nous vous demandons de bien vouloir indiquer l'hôpital dont l'adresse e-mail a été utilisée pour vous faire parvenir l'enquête. (Pour faciliter la recherche, les noms des hôpitaux figurant dans la liste déroulante ont été classés par ordre alphabétique. A côté du nom de l'institution, vous trouverez également le numéro d'accréditation).</i>	Sélectionnez le numéro d'agrément de votre hôpital	1 seule réponse Menu déroulant avec liste des numéros d'agrément
S1Q2*	Quelle est votre fonction/sont vos fonctions au sein de l'hôpital ?	○ Chef de la clinique de l'endométriose ○ Chef du service de gynécologie ○ Gynécologue possédant une expertise de l'endométriose ○ Gynécologue ○ Médecin-chef ○ Autre, précisez [champ libre]	Plusieurs réponses possibles
S1Q2 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S1Q3*	Votre hôpital a-t-il actuellement un ou plusieurs site(s) disposant d'une clinique de l'endométriose (centre d'expertise de l'endométriose) ? <i>En Belgique, les cliniques de l'endométriose ou centres d'expertise de l'endométriose ne font actuellement l'objet d'aucune reconnaissance officielle et il n'existe par conséquent pas de critères d'agrément officiels. Plusieurs hôpitaux ont toutefois créé de telles « cliniques de l'endométriose »</i>	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Si réponse ○ Oui > aller à S1Q4 ○ Non > aller à S3Q1



Code	Question	Réponses	Commentaire
	<i>par analogie p.ex. avec ce qui se fait à l'étranger.</i>		○ Je ne sais pas > aller à S3Q1
	<i>Dans cette enquête, c'est à ces initiatives que nous faisons référence lorsque nous parlons de cliniques de l'endométriose.</i>		
S1Q4*	Pouvez-vous sélectionner, pour votre hôpital, le ou les site(s) qui dispose(nt) d'une clinique de l'endométriose ?	Sélectionnez les sites	Plusieurs réponses possibles Menu déroulant avec liste des numéros d'agrément Prévoir l'option « Je ne sais pas » Aller à S2Q1

S2 – Organisation et fonctionnement de la clinique de l'endométriose

Code	Question	Réponses	Commentaire
	<i>Si votre hôpital dispose de plus d'un site avec une clinique de l'endométriose, nous vous demandons de répondre aux questions suivantes pour la clinique que vous connaissez le mieux et pour laquelle vos informations sont les plus précises.</i>		
S2Q1	En quelle année a été fondée la clinique de l'endométriose de votre hôpital ?	Spécifiez l'année où la clinique de l'endométriose de votre hôpital a été fondée.	1 seule réponse Menu déroulant avec les années de 1970 à aujourd'hui Prévoir l'option « Je ne sais pas »



Code	Question	Réponses	Commentaire
S2Q2*	Quels profils professionnels composent l'équipe de l'endométriose de votre hôpital ?	○ Médecin spécialiste en gynécologie-obstétrique ○ Médecin spécialiste en radiodiagnostic ○ Médecin spécialiste en chirurgie abdominale ○ Médecin spécialiste en chirurgie thoracique ○ Médecin spécialiste en anatomie pathologique ○ Médecin spécialiste en urologie ○ Médecin spécialiste rattaché à la clinique de la douleur ○ Médecin spécialiste en médecine physique et réadaptation ○ Médecin spécialiste en psychiatrie ○ Sage-femme ○ Sage-femme spécialisée ○ Infirmier ○ Infirmier spécialisé ○ Kinésithérapeute ○ Diététicien ○ Psychologue ○ Sexologue ○ Assistant social ○ Autre ○ Je ne sais pas	Plusieurs réponses possibles
S2Q2 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	



Code	Question	Réponses	Commentaire
S2Q3*	Un médecin spécialiste rattaché à la clinique de la fertilité fait-il partie de l'équipe d'endométriose de votre hôpital ?	☐ Oui ☐ Non ☐ Je ne sais pas	1 seule réponse
S2Q4*	Combien de nouvelles patientes avec une suspicion/un diagnostic d'endométriose la clinique de l'endométriose reçoit-elle en moyenne chaque mois ?	☐ <10 ☐ 10-20 ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ >50 ☐ Je ne sais pas	1 seule réponse
S2Q5*	Pour ces nouvelles patientes , quel est le délai d'attente moyen pour obtenir un premier rendez-vous à la clinique de l'endométriose de votre hôpital ?	☐ < 1 mois ☐ 1 à 3 mois ☐ 3 à 6 mois ☐ 6 à 9 mois ☐ ≥ 9 mois ☐ Je ne sais pas	1 seule réponse
S2Q6*	La clinique de l'endométriose de votre hôpital organise-t-elle une concertation multidisciplinaire sur l'endométriose où le diagnostic et le plan de traitement des patientes atteintes d'endométriose font l'objet d'une discussion par une équipe multidisciplinaire ?	☐ Oui ☐ Non ☐ Je ne sais pas	1 seule réponse Si réponse ☐ Oui > aller à S2Q7 ☐ Non > aller à S2Q10 ☐ Je ne sais pas > aller à S2Q10
S2Q7*	Quels sont les professions généralement présentes à la concertation multidisciplinaire sur l'endométriose où le diagnostic et le plan de traitement des patientes atteintes d'endométriose font l'objet d'une discussion par une équipe multidisciplinaire ?	☐ Médecin spécialiste en gynécologie-obstétrique ☐ Médecin spécialiste en radiodiagnostic	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
		○ Médecin spécialiste en chirurgie abdominale ○ Médecin spécialiste en chirurgie thoracique ○ Médecin spécialiste en anatomie pathologique ○ Médecin spécialiste en urologie ○ Médecin spécialiste rattaché à la clinique de la douleur ○ Médecin spécialiste en médecine physique et réadaptation ○ Médecin spécialiste en psychiatrie ○ Sage-femme ○ Sage-femme spécialisée ○ Infirmier ○ Infirmier spécialisé ○ Kinésithérapeute ○ Diététicien ○ Psychologue ○ Sexologue ○ Assistant social ○ Autre ○ Je ne sais pas	
S2Q7 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S2Q8*	Un médecin spécialiste travaillant à la clinique de la fertilité est-il généralement présent au cours de la concertation multidisciplinaire sur l'endométriose ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse
S2Q9*	Quels groupes de patientes sont généralement abordés à la concertation multidisciplinaire sur l'endométriose ?	○ Toutes les patientes atteintes d'une endométriose (suspectée)	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
	<i>Pour la définition de l'endométriose profonde, nous nous sommes basés sur les dernières recommandations de l'ESHRE (2022, p 53) : « Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter. »</i>	○ Les patientes atteintes d'une endométriose (suspectée) chez qui est prévue une opération chirurgicale ○ Les patientes atteintes d'une endométriose profonde (suspectée) chez qui est prévue une opération chirurgicale ○ Les patientes atteintes d'une endométriose (suspectée) et de troubles de la fertilité ○ Autre ○ Je ne sais pas	
S2Q9 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S2Q10 *	Qui réfère régulièrement des patientes avec une endométriose (suspectée/diagnostiquée) à la clinique de l'endométriose de votre hôpital ?	○ Des médecins exerçant dans des hôpitaux du même réseau locorégional ○ Des médecins exerçant dans des hôpitaux n'appartenant pas au même réseau locorégional ○ Des médecins spécialistes en gynécologie-obstétrique exerçant en cabinet privé ○ Des médecins généralistes ○ Des médecins de centres PSE (Promotion Santé à l'Ecole) ○ Des médecins du travail ○ Des médecins-conseils (<i>médecins rattachés à une mutuelle, qui évaluent si une personne répond aux conditions de reconnaissance de</i>	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
		<i>l'incapacité de travail pour l'octroi d'une indemnité)</i> ○ Des médecins-contrôle (<i>chargés par l'employeur de contrôler si un travailleur absent l'est pour des raisons justifiées</i>) ○ Des médecins de l'étranger ○ Des kinésithérapeutes ○ Des patientes se présentent de leur propre initiative ○ Autre ○ Je ne sais pas	
S2Q10 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S2Q11 *	À la clinique de l'endométriose de votre hôpital, y a-t-il un membre du personnel chargé d'assurer la coordination et la continuité des soins (comme le font les infirmiers du sein dans les cliniques du sein) ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Si réponse ○ Oui > aller à S2Q12 ○ Non > aller à S2Q13 ○ Je ne sais pas > aller à S2Q13
S2Q12 *	Qui est responsable de la coordination et de la continuité des soins à la clinique de l'endométriose de votre hôpital ?	○ Une sage-femme ○ Une sage-femme spécialisée ○ Un infirmier ○ Un infirmier spécialisé ○ Un gynécologue de la clinique de l'endométriose ○ Autre ○ Je ne sais pas	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
S2Q12 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S2Q13 *	Combien d' opérations en raison d'une (suspicion d') endométriose la clinique de l'endométriose de votre hôpital réalise-t-elle en moyenne par MOIS ?	○ Aucune ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Je ne sais pas	1 seule réponse
S2Q14 *	Combien d' opérations en raison d'une (suspicion d') endométriose PROFONDE la clinique de l'endométriose de votre hôpital réalise-t-elle en moyenne par AN ? <i>Pour la définition de l'endométriose profonde, nous nous sommes basés sur les dernières recommandations de l'ESHRE (2022, p 53) : « Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter. »</i>	○ Aucune ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Je ne sais pas	1 seule réponse
S2Q15 *	Y a-t-il des patientes atteintes d'une forme spécifique d'endométriose que la clinique de l'endométriose de votre hôpital réfère à d'autres centres belges possédant une expertise (spécifique) plus poussée de la chirurgie de l'endométriose ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Si réponse ○ Oui > aller à S2Q16 ○ Non > aller à S2Q17 ○ Je ne sais pas > aller à S2Q17



Code	Question	Réponses	Commentaire
S2Q16	Quelles sont les patientes que la clinique de l'endométriose de votre hôpital réfère à d'autres centres belges possédant une expertise (spécifique) plus poussée de la chirurgie de l'endométriose ?	[champ libre]	
S2Q17 *	La clinique de l'endométriose de votre hôpital réfère-t-il des patientes à des centres étrangers possédant une expertise (spécifique) plus poussée de la chirurgie de l'endométriose ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Si réponse ○ Oui > aller à S2Q18 ○ Non > aller à S4Q1 ○ Je ne sais pas > aller à S4Q1
S2Q18	Quelles patientes de la clinique de l'endométriose de votre hôpital sont référées vers des centres étrangers possédant une expertise (spécifique) plus poussée de la chirurgie de l'endométriose ?	[champ libre]	Aller à S4Q1

**S3 – Organisation des soins aux patientes atteintes d'endométriose dans les hôpitaux sans clinique de l'endométriose**

Code	Question	Réponses	Commentaire
S3Q1*	Quand une patiente avec une suspicion d'endométriose se présente dans votre hôpital, vers qui est-elle habituellement orientée pour un avis et/ou des examens diagnostiques ?	○ L'un des gynécologues de votre hôpital sans expertise spécifique dans le domaine de l'endométriose ○ Un gynécologue de votre hôpital possédant une expertise spécifique dans le domaine de l'endométriose ○ Un radiologue de votre hôpital sans expertise spécifique dans le domaine de l'endométriose ○ Un radiologue de votre hôpital possédant une expertise spécifique dans le domaine de l'endométriose ○ Une clinique de l'endométriose à l'intérieur du même réseau locorégional ○ Une clinique de l'endométriose en-dehors de votre réseau locorégional ○ Autre ○ Je ne sais pas	Plusieurs réponses possibles
S3Q2 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S3Q2*	Votre hôpital organise-t-il une concertation multidisciplinaire sur l'endométriose où le diagnostic et le plan de traitement des patientes atteintes d'endométriose font l'objet d'une discussion par une équipe multidisciplinaire ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Si réponse ○ Oui > aller à S3Q3 ○ Non > aller à S3Q6



Code	Question	Réponses	Commentaire
			○ Je ne sais pas > aller à S3Q6
S3Q3*	Quels sont les professions généralement présentes à la concertation multidisciplinaire sur l'endométriose où le diagnostic et le plan de traitement des patientes atteintes d'endométriose font l'objet d'une discussion par une équipe multidisciplinaire ?	○ Médecin spécialiste en gynécologie-obstétrique ○ Médecin spécialiste en radiodiagnostic ○ Médecin spécialiste en chirurgie abdominale ○ Médecin spécialiste en chirurgie thoracique ○ Médecin spécialiste en anatomie pathologique ○ Médecin spécialiste en urologie ○ Médecin spécialiste rattaché à la clinique de la douleur ○ Médecin spécialiste en médecine physique et réadaptation ○ Médecin spécialiste en psychiatrie ○ Sage-femme ○ Sage-femme spécialisée ○ Infirmier ○ Infirmier spécialisé ○ Kinésithérapeute ○ Diététicien ○ Psychologue ○ Sexologue ○ Assistant social ○ Autre ○ Je ne sais pas	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
S3Q3 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S3Q4*	Un médecin spécialiste travaillant à la clinique de la fertilité est-il généralement présent au cours de la concertation multidisciplinaire sur l'endométriose ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse
S3Q5*	Quels groupes de patientes sont habituellement abordés à la concertation multidisciplinaire sur l'endométriose ?	○ Toutes les patientes atteintes d'une endométriose (suspectée) ○ Les patientes atteintes d'une endométriose (suspectée) chez qui est prévue une opération chirurgicale ○ Les patientes atteintes d'une endométriose profonde (suspectée) chez qui est prévue une opération chirurgicale ○ Les patientes atteintes d'une endométriose (suspectée) et de troubles de la fertilité ○ Autre ○ Je ne sais pas	Plusieurs réponses possibles
S3Q5 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S3Q7*	Dans votre hôpital, lorsqu'une endométriose (hors endométriose profonde) est suspectée ou diagnostiquée chez une patiente, elle est généralement adressée/référée pour le traitement chirurgical... <i>Pour la définition de l'endométriose profonde, nous nous sommes basés sur les dernières recommandations de l'ESHRE (2022, p 53) : « Deep</i>	○ À l'un des gynécologues de votre hôpital (sans expertise spécifique en endométriose) ○ À un gynécologue de votre hôpital possédant une expertise spécifique de la chirurgie de l'endométriose ○ À un spécialiste en chirurgie générale de votre hôpital	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
	<i>endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter. »</i>	- possédant une expertise spécifique de la chirurgie de l'endométriose ○ À une clinique de l'endométriose à l'intérieur du même réseau locorégional ○ À une clinique de l'endométriose en-dehors de votre réseau locorégional ○ À une clinique de l'endométriose à l'étranger ○ Autre ○ Je ne sais pas	
S3Q7 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S3Q8*	Dans votre hôpital, lorsqu'une endométriose profonde est suspectée ou diagnostiquée chez une patiente, elle est généralement adressée/référée pour le traitement chirurgical... <i>Pour la définition de l'endométriose profonde, nous nous sommes basés sur les dernières recommandations de l'ESHRE (2022, p 53) : « Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter. »</i>	○ À l'un des gynécologues de votre hôpital (sans expertise spécifique en endométriose) ○ À un gynécologue de votre hôpital possédant une expertise spécifique de la chirurgie de l'endométriose ○ À un spécialiste en chirurgie générale de votre hôpital possédant une expertise spécifique de la chirurgie de l'endométriose ○ À une clinique de l'endométriose à l'intérieur du même réseau locorégional ○ À une clinique de l'endométriose en-dehors de votre réseau locorégional	Plusieurs réponses possibles



Code	Question	Réponses	Commentaire
		○ À une clinique de l'endométriose à l'étranger ○ Autre ○ Je ne sais pas	
S3Q8 bis	Vous avez répondu "Autre" à la question précédente. Pouvez-vous préciser cette réponse ?	[champ libre]	
S3Q9*	Combien d' opérations en raison d'une (suspicion d') endométriose sont réalisées en moyenne par MOIS dans votre hôpital ?	○ Aucune ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Je ne sais pas	1 seule réponse
S3Q10 *	Combien d' opérations profondes en raison d'une (suspicion d') endométriose sont réalisées en moyenne par AN dans votre hôpital? <i>Pour la définition de l'endométriose profonde, nous nous sommes basés sur les dernières recommandations de l'ESHRE (2022, p 53) : « Deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder, or ureter. »</i>	○ Aucune ○ 1-5 ○ 6-10 ○ 11-20 ○ 21-30 ○ 31-40 ○ 41-50 ○ >50 ○ Je ne sais pas	1 seule réponse
S3Q11 *	Jusqu'ici, dans quelle mesure êtes-vous satisfait(e) de la collaboration avec la ou les clinique(s) de l'endométriose à laquelle/auxquelles vous référez des patientes ?	○ Très satisfait(e) ○ Satisfait(e) ○ Pas satisfait(e) ○ Pas du tout satisfait(e) ○ Je ne sais pas	1 seule réponse



Code	Question	Réponses	Commentaire
		○ Je ne réfère pas des patientes à une clinique de l'endométriose	
S3Q12	Merci de bien vouloir expliciter votre réponse à la question précédente	[champ libre]	
S3Q13 *	La création d'une clinique de l'endométriose dans votre hôpital est-elle prévue dans un avenir proche ?	○ Oui ○ Non ○ Je ne sais pas	1 seule réponse Aller à S4Q1

S4 – Améliorer les soins aux patientes atteintes d'endométriose

Code	Question	Réponses	Commentaire
S4Q1	D'après vous, comment les soins aux patientes atteintes d'endométriose pourraient-ils être améliorés au sein de votre hôpital ?	[champ libre]	
S4Q2	D'après vous, comment les soins aux patientes atteintes d'endométriose pourraient-ils être améliorés en général (y compris en-dehors de votre hôpital) ?	[champ libre]	Allee à S5Q1

S5 – Remarques complémentaires

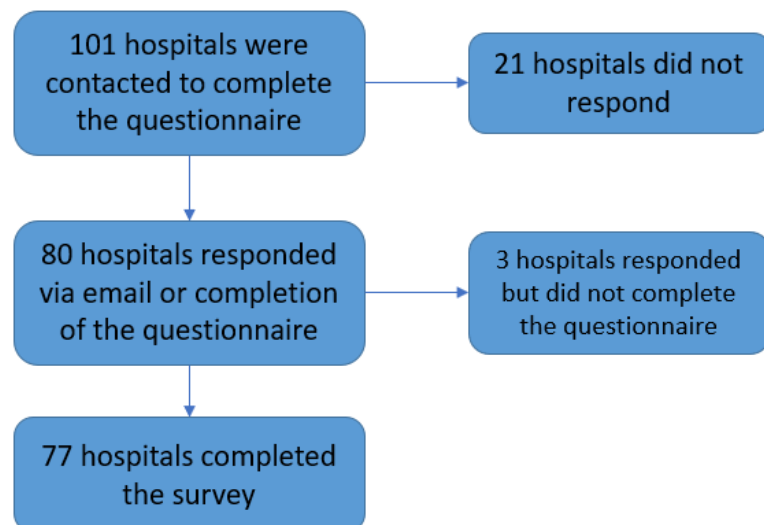
Code	Question	Réponses	Commentaire
S5Q1	Si vous souhaitez nous faire part d'autres concernant le contenu de cette enquête ou concernant l'étude du KCE, nous vous remercions de bien vouloir les indiquez ci-après ?	[champ libre]	

Nous vous remercions d'avoir pris le temps de compléter cette enquête. Pour toute question, vous pouvez contacter xx (x.x@kce.fgov.be).



Appendix 4.3. Flowchart of responses to the questionnaire invitation

Figure 13 – Flowchart of responses to the questionnaire invitation



Appendix 4.4. List of hospitals that responded to the survey, by region

Table 34 – List of hospitals that responded to the survey, by region

Hospitals by region – License number
Flemish region
AZ Alma - 032
AZ Damiaan – 525
AZ Diest – 712
AZ Groeninge – 396
AZ Herentals – 308
AZ Jan Palfijn – 713
AZ Klina – 710
AZ Maria Middelaers – 017
AZ Monica – 682
AZ Oudenaarde – 170
AZ Sint-Blasius – 012
AZ Sint-Elisabeth – 217
AZ Sint-Jan – 049
AZ Sint-Lucas (Brugge) – 140
AZ Sint-Lucas (Gent) – 290
AZ Sint-Vincentius – 134
AZ Turnhout – 063
AZ Vesalius – 716
AZ Voorkempen – 536
AZ Zeno – 392
GZA – ziekenhuizen – 099
Heilig Hart ziekenhuis (Mol) – 102
Imelda ziekenhuis – 689
Jan Yperman ziekenhuis – 057
Jessa ziekenhuis – 243



Hospitals by region – License number

O.L.V. Van Lourdes ziekenhuis Waregem – 397
Onze-Lieve-Vrouw ziekenhuis – 126
Regionaal ziekenhuis Heilig Hart – 108
RZ Heilig Hart Tienen – 109
Sint-Andriesziekenhuis – 395
Sint-Franciscusziekenhuis – 714
Sint-Trudo ziekenhuis – 715
St-Jozefskliniek – 124
Universitair ziekenhuis Antwerpen (UZA) – 300
Universitair ziekenhuis Gent – 670
UZ Leuven – 322
Vitaz – 595
Ziekenhuis Oost-Limburg (Genk) – 371
Ziekenhuis Oost-Limburg (Maaseik) – 717

Walloon region

Centre de Santé Des Fagnes – 249
Centre Hospitalier Bois de l'Abbaye – 042
Centre Hospitalier Centre Ardenne – 168
Centre Hospitalier de Mouscron – 247
Hospitalier de Wallonie Picarde (CHwapi) – 534
Centre Hospitalier Epicura (Ath) – 724
Centre Hospitalier Epicura (Hornu) – 410
Centre Hospitalier Regional Haute Senne – 007
Centre Hospitalier Reine Astrid – 004
CHR de Huy - 068
CHR Sambre et Meuse (Auvelais) – 103
CHR Sambre et Meuse (Namur) – 006
CHU Ambroise Paré – 254
CHU Charleroi (Lodelinsart) – 718
CHU Charleroi (Montigny-le-Tilleul) – 325
CHU de Liège – 707

Hospitals by region – License number

CHU Tivoli – 096
CHU-UCL Namur – Hôpital Dinant – 264
CHU-UCL Namur (Mont-Godinne) – 039
CHU-UCL Namur (Namur) – 166
Clinique André Renard – 023
Clinique Notre-Dame de Grace – 409
Clinique Saint Pierre – 043
Grand Hôpital de Charleroi – 010
Groupe Santé CHC (Liège) – 152
Hôpital de la Citadelle – 412
Klinik St. Josef – 257
Pôle Hospitalier Jolimont (Haine-Saint-Paul) – 146
Pôle Hospitalier Jolimont (Nivelles-Tubize) – 346
St.-Nikolaus Hospital – 015
Vivalia (Arlon) – 246

Brussels-Capital

CHIREC – Hôpital Delta – 332
CHIREC – Hôpital SARE – 723
CHU Saint-Pierre / UMC Sint-Pieter – 076
Clinique Saint-Luc – 706
Europaziekenhuizen – Cliniques de l'Europe – 111
Hôpital Erasme (ULB) – 406
Hôpitaux Iris Sud – Iris Ziekenhuizen Zuid – 087
Institut Jules Bordet – 079
Kliniek Sint-Jan – Clinique Saint-Jean – 110
Universitair Ziekenhuis Brussel – 143

Note: Within each subcategory, the hospitals are listed in alphabetical order; the principal sites of hospital CHIREC - Hôpital SARE (with license number 723; i.e. the Clinique St-Anne and St-Rémi) are located in Brussels capital region, but a third hospital site is located in Braine L'Alleud, in the Walloon region.



Appendix 4.5. List of hospitals with self-reported endometriosis clinic

Table 35 – List of hospitals with self-reported endometriosis clinic

Hospitals with self-reported endometriosis clinic – Licence number	Campus(es) with endometriosis clinic	Year start of endometriosis clinic
Flemish region		
AZ Damiaan – 525		2020
AZ Diest – 712	Hasseltsestraat	2014
AZ Groeninge – 396	Kennedylaan	2018
AZ Jan Palfijn – 713		2017
AZ Sint-Jan – 049	Sint-Jan	2022
AZ Turnhout – 063	Sint-Jozef	2012
GZA – ziekenhuizen – 099	Sint-Augustinus	2013
Jessa Ziekenhuis – 243	Virga Jesse & Salvator	2014
O.L.V. Van Lourdes ziekenhuis Waregem – 397		2010
Regionaal ziekenhuis Heilig Hart – 108		1998
Sint-Jozefskliniek – 124		2010
Universitair Ziekenhuis Antwerpen (UZA) – 300		2017
Universitair Ziekenhuis Gent – 670		2003
UZ Leuven – 322	Gasthuisberg	1996
Ziekenhuis Oost-Limburg – 371	Sint-Jan	
Walloon region		
Centre Hospitalier de Wallonie Picarde (CHwapi) – 534	Union	2023
CHU Ambroise Paré – 254		2017
CHU de Liège – 707	Notre Dame des Bruyères	2018



Hospitals with self-reported endometriosis clinic – Licence number	Campus(es) with endometriosis clinic	Year start of endometriosis clinic
CHU Tivoli – 096		2021
Clinique André Renard – 023		2022
Clinique Saint Pierre – 043		2000
Grand Hôpital de Charleroi - 010	Notre Dame & Saint-Joseph	2018
Groupe Santé CHC (Liège) – 152	Clinique CHC Montlegia	2009
Hôpital de la Citadelle – 412	Citadelle & Laveu	2018
Brussels-Capital region		
CHIREC – Hôpital Delta – 332	Delta	2023
CHU Saint-Pierre / UMC Sint-Pieter – 076	Hallepoort & Cesar de Paepe	2023
Clinique Saint-Luc – 706		2023
Hôpital Erasme (ULB) – 406		2021
Hôpitaux Iris Sud – Iris Ziekenhuizen Zuid – 087	Etterbeek-Ixelles	2023
Universitair Ziekenhuis Brussel – 143		2021



Appendix 4.6. Additional results of the hospital survey

Table 36 – Activities in endometriosis clinics, by presence of MDT meetings

	All endometriosis clinics (n=30)	Clinics with MDT for endometriosis (n=23)	Clinics without MDT for endometriosis (n=7)
Number of new patients per month			
< 10	1 (3.3%)	1 (4.3%)	0
10-20	12 (40.0%)	7 (30.4%)	5 (71.4%)
21-30	5 (16.7%)	4 (17.4%)	1 (14.3%)
31-40	2 (6.7%)	2 (8.7%)	0
41-50	3 (10.0%)	2 (8.7%)	1 (14.3%)
> 50	5 (16.7%)	5 (21.7%)	0
Unknown	2 (6.7%)	2 (8.7%)	0
Number of surgeries for endometriosis (excluding deep endometriosis) per <u>month</u>			
1-5	4 (13.3%)	3 (13.0%)	1 (14.3%)
6-10	12 (40.0%)	7 (30.4%)	5 (71.4%)
11-20	7 (23.3%)	6 (26.1%)	1 (14.3%)
21-30	5 (16.7%)	5 (21.7%)	0
Unknown	2 (6.7%)	2 (8.7%)	0
Number of surgeries for deep endometriosis per <u>year</u>			
None	1 (3.3%)	0	1 (14.3%)
1-5	1 (3.3%)	1 (4.3%)	0
6-10	7 (23.3%)	6 (26.1%)	1 (14.3%)
11-20	3 (10.0%)	2 (8.7%)	1 (14.3%)
21-30	6 (20.0%)	3 (13.0%)	3 (42.9%)



	All endometriosis clinics (n=30)	Clinics with MDT for endometriosis (n=23)	Clinics without MDT for endometriosis (n=7)
Number of new patients per month			
31-40	3 (10.0%)	3 (13.0%)	0
41-50	3 (10.0%)	2 (8.7%)	1 (14.3%)
> 50	4 (13.3%)	4 (17.4%)	0
Unknown	2 (6.7%)	2 (8.7%)	0

MDT: multidisciplinary team; 'deep endometriosis', as defined by ESHRE, 2022.³³

Table 37– Professions that refer to endometriosis clinics

Referrals*	Number of endometriosis clinics (n=30; %)
Physicians from the same hospital network	30 (100%)
General practitioners	29 (96.7%)
Patient's own initiative	27 (90.0%)
Gynaecologists (Private practices)	25 (83.3%)
Physicians from another network	20 (66.7%)
Physiotherapists	10 (33.3%)
Physicians from abroad	6 (20.0%)
#	5 (16.7%)

*: Multiple answers were possible for this question, hence the various subtotals add up to >100%; #: other: five hospitals reported that they also receive referrals from medical control physicians (check whether absent employees are legitimately absent), osteopaths (specialism open for physicians and physiotherapists, that is currently not officially recognized in Belgium), dieticians, psychologists, sexologists, colleagues of the fertility centre, gastro-enterologists and acupuncturists (not officially recognized either).

Table 38 – Surgical case load of hospitals without endometriosis clinic, by MDT

	Hospitals without endometriosis clinic (n=47)
Number of surgeries for endometriosis (excluding deep endometriosis) per month	
None	3 (6.4%)
1-5	24 (51.1%)
6-10	13 (27.7%)
11-20	0
21-30	1 (2.1%)
Not known	6 (12.8%)
Number of surgeries for deep endometriosis per year	
None	18 (38.3%)
1-5	11 (23.4%)
6-10	4 (8.5%)
11-20	6 (12.8%)
21-30	1 (2.1%)
31-40	0
41-50	0
> 50	0
Not known	7 (14.9%)

**Table 39 – Referral patterns in hospitals without endometriosis clinic**

	For diagnosis of endometriosis	For surgical treatment of endometriosis (excluding deep endometriosis)	For surgical treatment of deep endometriosis
Only within own hospital	28 (59.6%)	23 (48.9%)	11 (23.4%)
Within own hospital or to endometriosis clinic within network	4 (8.5%)	4 (8.5%)	3 (6.4%)
Within own hospital or to endometriosis clinic outside of network	5 (10.6%)	6 (12.8%)	6 (12.8%)
Within own hospital or to endometriosis clinic within or outside of network	2 (4.3%)	3 (6.4%)	0
Only to endometriosis clinic within network	4 (8.5%)	5 (10.6%)	7 (14.9%)
To endometriosis clinic within or outside of network	1 (2.1%)	3 (6.4%)	4 (8.5%)
Only to endometriosis clinic outside of network	1 (2.1%)	2 (4.3%)	16 (34.0%)
Other country	0	0	0
Unknown	1 (2.1%)	0	0
Other	1 (2.1%) ^f	1 (2.1%) ^g	0

f: Within own hospital, to endometriosis clinic within network and to a specialized gynaecologist outside of network; g: referral to a specialist in another hospital



APPENDIX 5. ORGANISATION OF ENDOMETRIOSIS CARE ABROAD

Appendix 5.1. General search strategies

Appendix 5.1.1. Medline

Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to August 03, 2023>	
Date	3 August 2023	
Search strategy		Number of hits
1	endometriosis/	25600
2	adenomyosis/	1252
3	1 or 2	26486
4	(endometrios#s or endometrioma? or adenomyos#s or adenomyoma? or adenometrit#s or adenomyosit#s or adenomyometrit#s).ti,ab,kf.	32710
5	3 or 4	35888
6	(gyn?ecolog\$ adj3 (cent\$ or clinic? or service?)).ti,ab,kf.	6753
7	((cent\$ or network\$) adj2 (excellence or expert\$)).ti,ab,kf.	6825
8	(speciali\$ adj3 (cent\$ or clinic? or service? or team?)).ti,ab,kf.	32488
9	6 or 7 or 8	45686
10	5 and 9	365
11	endocent\$.ti,ab,kf.	6
12	((endometrios#s or adenomyos#s) adj3 (cent\$ or clinic? or service?)).ti,ab,kf.	372
13	((endometrios#s or adenomyos#s) adj3 MDT).ab,ti,kf.	0
14	((endometrios#s or adenomyos#s) adj3 (registry or registries)).ab,ti,kf.	7
15	11 or 12 or 13 or 14	384
16	10 or 15	691
17	PATIENT CARE TEAM/	69490
18	((((patient\$ or medical or health) adj1 care team) or healthcare team).ti,ab,kf.	7872



Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to August 03, 2023>	
19	((multidisciplin\$ or interdisciplin\$ or transdisciplin\$ or multi-disciplin\$ or inter-disciplin\$ or trans-disciplin\$) adj3 (cent\$ or clinic? or service? or care or team? or group? or staff or task force or approach or program\$ or system? or panel? or forum? or manag\$ or treat\$)).ti,ab,kf.	108398
20	((multiprofess\$ or interprofess\$ or transprofess\$ or multi-profess\$ or inter-profess\$ or trans-profess\$ or integrated or network) adj3 (cent\$ or clinic? or service? or care or team? or group? or staff or task force or approach or program\$ or system? or panel? or forum? or manag\$ or treat\$)).ti,ab,kf.	115314
21	17 or 18 or 19 or 20	277671
22	5 and 21	401
23	INTERDISCIPLINARY COMMUNICATION/	18138
24	((multiprofess\$ or interprofess\$ or transprofess\$ or multi-profess\$ or inter-profess\$ or trans-profess\$ or integrated) adj3 (communic\$ or network? or collaborat\$ or relation\$)).ti,ab,kf.	13573
25	((multidisciplin\$ or interdisciplin\$ or transdisciplin\$ or multi-disciplin\$ or inter-disciplin\$ or trans-disciplin\$) adj3 (communic\$ or network? or collaborat\$ or relation\$)).ti,ab,kf.	10890
26	(network meeting? or network communicat\$).ti,ab,kf.	706
27	24 or 25 or 26	24784
28	23 or 27	41619
29	5 and 28	36
30	"Delivery of Health Care"/	117318
31	"Delivery of Health Care, Integrated"/	14298
32	30 or 31	131243
33	((delivery or organi#ation) adj3 "health care").ab,ti,kf.	28487
34	((delivery or organi#ation) adj3 "healthcare").ab,ti,kf.	11554
35	("health care" adj3 system?).ab,ti,kf.	56645
36	(healthcare adj3 system?).ab,ti,kf.	49459
37	(integrated adj3 "health care").ab,ti,kf.	3583
38	(integrated adj3 "healthcare").ab,ti,kf.	2400
39	33 or 34 or 35 or 36 or 37 or 38	137737



Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to August 03, 2023>	
40	32 or 39	242563
41	5 and 40	93
42	public policy/	33656
43	exp health policy/	133159
44	42 or 43	164701
45	((public or health) adj3 (policy or policies or plan?)).ab,ti,kf.	100218
46	((regional or national or international or multiregional) adj3 (plan? or policy or policies)).ab,ti,kf.	21066
47	45 or 46	115950
48	44 or 47	253548
49	5 and 48	33
50	16 or 22 or 29 or 41 or 49	1168
51	((recognition or recogniz*) adj6 chronic).ab,ti,kf.	4413
52	((acceptance or accept*) adj6 chronic).ab,ti,kf.	1900
53	(acknowledg* adj6 chronic).ab,ti,kf.	221
54	((perception or perceiv* or consider*) adj6 chronic).ab,ti,kf.	14665
55	51 or 52 or 53 or 54	21042
56	5 and 55	66
57	Quality Indicators, Health Care/	17408
58	"Quality of Health Care"/	77521
59	57 or 58	92684
60	(quality adj3 indicator?).ab,ti,kf.	18041
61	(quality adj3 care).ab,ti,kf.	100423
62	(quality adj3 healthcare).ab,ti,kf.	12706
63	(quality adj3 "health care").ab,ti,kf.	18155
64	(health adj2 metric?).ab,ti,kf.	1400



Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to August 03, 2023>	
65	trigger tool?.ab,ti,kf.	429
66	benchmarking.ab,ti,kf.	12198
67	(quality adj3 measure?).ab,ti,kf.	35493
68	(quality adj3 assessment).ab,ti,kf.	45901
69	60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68	207042
70	59 or 69	267483
71	5 and 70	226
72	16 or 22 or 29 or 41 or 49 or 56 or 71	1405
73	limit 72 to yr="2013-2023"	980
74	remove duplicates from 73	976

Appendix 5.1.2. Cochrane

Database	Cochrane	
Date	7 August 2023	
Search strategy		Number of hits
#1	[mh ^"endometriosis"]	1201
#2	[mh ^"adenomyosis"]	72
#3	#1 or #2	1266
#4	(endometrios?s or endometrioma? or adenomyos?s or adenomyoma? or adenometrit?s or adenomyosit?s or adenomyometrit?s):ab,ti	3134
#5	#3 or #4	3242
#6	(gyn?ecolog* NEAR/3 (cent* or clinic? or service?)):ab,ti	913
#7	((cent* or network*) NEAR/2 (excellence or expert*)):ab,ti	567
#8	(speciali* NEAR/3 (cent* or clinic? or service? or team?)):ab,ti	3571
#9	#6 or #7 or #8	5013
#10	#5 and #9	47



Database	Cochrane	
#11	endocent*:ab,ti	0
#12	((endometrios?s or adenomyos?s) NEAR/3 (cent* or clinic? or service?)):ab,ti	39
#13	((endometrios?s or adenomyos?s) NEAR/3 MDT):ab,ti	0
#14	((endometrios?s or adenomyos?s) NEAR/3 (registry or registries)):ab,ti	2
#15	#11 or #12 or #13 or #14	40
#16	#10 or #15	83
#17	[mh ^"PATIENT CARE TEAM"]	2021
#18	((patient* or medical or health) NEAR/1 "care team") or "healthcare team"):ab,ti	691
#19	((multidisciplin* or interdisciplin* or transdisciplin* or multi-disciplin* or inter-disciplin* or trans-disciplin*) NEAR/3 (cent* or clinic? or service? or care or team? or group? or staff or "task force" or approach or program* or system? or panel? or forum? or manag* or treat*)):ab,ti	7043
#20	((multiprofess* or interprofess* or transprofess* or multi-profess* or inter-profess* or trans-profess* or integrated or network) NEAR/3 (cent* or clinic? or service? or care or team? or group? or staff or "task force" or approach or program* or system? or panel? or forum? or manag* or treat*)):ab,ti	9583
#21	#17 or #18 or #19 or #20	18031
#22	#5 and #21	15
#23	[mh ^"INTERDISCIPLINARY COMMUNICATION"]	321
#24	((multiprofess* or interprofess* or transprofess* or multi-profess* or inter-profess* or trans-profess* or integrated) NEAR/3 (communic* or network? or collaborat* or relation*)):ab,ti	510
#25	((multidisciplin* or interdisciplin* or transdisciplin* or multi-disciplin* or inter-disciplin* or trans-disciplin*) NEAR/3 (communic* or network? or collaborat* or relation*)):ab,ti	420
#26	("network meetings" or "network meeting" or (network NEAR/1 communicat*)):ab,ti	73
#27	#24 or #25 or #26	984
#28	#23 or #27	1289
#29	#5 and #28	0
#30	[mh ^"Delivery of Health Care"]	1369
#31	[mh ^"Delivery of Health Care, Integrated"]	518
#32	#30 or #31	1880



Database	Cochrane	
#33	((delivery or organi?ation) NEAR/3 "health care"):ab,ti	619
#34	((delivery or organi?ation) NEAR/3 "healthcare"):ab,ti	531
#35	("health care" NEAR/3 system?):ab,ti	3226
#36	(healthcare NEAR/3 system?):ab,ti	3708
#37	(integrated NEAR/3 "health care"):ab,ti	259
#38	(integrated NEAR/3 healthcare):ab,ti	208
#39	#33 or #34 or #35 or #36 or #37 or #38	7608
#40	#32 or #39	9227
#41	#5 and #40	6
#42	[mh ^"public policy"]	91
#43	[mh "health policy"]	2777
#44	#42 or #43	2861
#45	((public or health) NEAR/3 (policy or policies or plan?)):ab,ti	2909
#46	((regional or national or international or multiregional) NEAR/3 (plan? or policy or policies)):ab,ti	614
#47	#45 or #46	3421
#48	#44 or #47	6124
#49	#5 and #48	4
#50	#16 or #22 or #29 or #41 or #49	106
#51	((recognition or recogniz*) NEAR/6 chronic):ab,ti	185
#52	((acceptance or accept*) NEAR/6 chronic):ab,ti	424
#53	(acknowledg* NEAR/6 chronic):ab,ti	19
#54	((perception or perceiv* or consider*) NEAR/6 chronic):ab,ti	1233
#55	#51 or #52 or #53 or #54	1851
#56	#5 and #55	8
#57	[mh ^"Quality Indicators, Health Care"]	292
#58	[mh ^"Quality of Health Care"]	1156



Database	Cochrane	
#59	#57 or #58	1415
#60	(quality NEAR/3 indicator?):ab,ti	1109
#61	(quality NEAR/3 care):ab,ti	6673
#62	(quality NEAR/3 healthcare):ab,ti	590
#63	(quality NEAR/3 "health care"):ab,ti	668
#64	(health NEAR/2 metric?):ab,ti	66
#65	(trigger NEAR/1 tool?):ab,ti	39
#66	benchmarking:ab,ti	278
#67	(quality NEAR/3 measure?):ab,ti	9811
#68	(quality NEAR/3 assessment):ab,ti	4628
#69	#60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68	21911
#70	#59 or #69	22599
#71	#5 and #70	52
#72	#16 or #22 or #29 or #41 or #49 or #56 or #71	156
#73	#72 with Cochrane Library publication date Between Jan 2013 and Dec 2023	135



Appendix 5.2. Search strategies on the association between caseload and outcome in endometriosis care

Appendix 5.2.1. Medline

Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to October 12, 2023>	
Date	12 October 2023	
Search strategy		Number of hits
1	endometriosis/	25811
2	adenomyosis/	1279
3	1 or 2	26717
4	(endometriosis#s or endometrioma? or adenomyosis#s or adenomyoma? or adenometritis#s or adenomyositis#s or adenomyometritis#s).ti,ab,kf.	33091
5	3 or 4	36277
6	exp "Hospitals, High-Volume"/	2074
7	exp "Hospitals, Low-Volume"/	1042
8	6 or 7	2227
9	caseload.ab,ti,kf.	3757
10	workload.ab,ti,kf.	34075
11	volume-outcome.ab,ti,kf.	1011
12	(hospital adj2 volume?).ab,ti,kf.	3955
13	"hospital size".ab,ti,kf.	1115
14	"clinic size".ab,ti,kf.	88
15	((center or centre) adj2 volume?).ab,ti,kf.	3907
16	((center or centre) adj2 size).ab,ti,kf.	472
17	(patient adj2 volume?).ab,ti,kf.	3801
18	(provider adj2 volumes).ab,ti,kf.	38
19	(doctor adj2 volumes).ab,ti,kf.	2
20	(procedure adj2 volume?).ab,ti,kf.	1344



Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to October 12, 2023>	
21	(procedural adj2 volume?).ab,ti,kf.	636
22	(facility adj2 volume?).ab,ti,kf.	321
23	(treatment adj2 volume?).ab,ti,kf.	4368
24	(surgical adj2 volume?).ab,ti,kf.	2982
25	(surgery adj2 volume?).ab,ti,kf.	2984
26	(surgeon? adj2 volume?).ab,ti,kf.	2430
27	(operation? adj2 volume?).ab,ti,kf.	704
28	centrali?ation.ab,ti,kf.	4297
29	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28	66884
30	8 or 29	67573
31	5 and 30	63
32	limit 31 to yr="2013-Current"	50

Appendix 5.2.2. Cochrane

Database	Cochrane	
Date	13 October 2023	
Search strategy		Number of hits
#1	[mh ^endometriosis]	1210
#2	[mh ^adenomyosis]	72
#3	#1 OR #2	1275
#4	(endometrios?s:ti,ab,kw OR endometrioma?:ti,ab,kw OR adenomyos?s:ti,ab,kw OR adenomyoma?:ti,ab,kw OR adenometrit?s:ti,ab,kw OR adenomyosit?s:ti,ab,kw OR adenomyometrit?s:ti,ab,kw)	3409
#5	#3 OR #4	3409



Database	Cochrane	
#6	[mh "Hospitals, High-Volume"]	19
#7	[mh "Hospitals, Low-Volume"]	12
#8	#6 OR #7	20
#9	caseload:ti,ab,kw	261
#10	workload:ti,ab,kw	4351
#11	volume-outcome:ti,ab,kw	27
#12	(hospital:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	510
#13	"hospital size":ti,ab,kw	31
#14	"clinic size":ti,ab,kw	19
#15	((center:ti,ab,kw OR centre:ti,ab,kw) NEAR/2 volume?:ti,ab,kw)	250
#16	((center:ti,ab,kw OR centre:ti,ab,kw) NEAR/2 size:ti,ab,kw)	118
#17	(patient:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	670
#18	(provider:ti,ab,kw NEAR/2 volumes:ti,ab,kw)	2
#19	(doctor:ti,ab,kw NEAR/2 volumes:ti,ab,kw)	0
#20	(procedure:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	215
#21	(procedural:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	26
#22	(facility:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	14
#23	(treatment:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	821
#24	(surgical:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	179
#25	(surgeon?:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	141
#26	(operation?:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	168
#27	centrali?ation:ti,ab,kw	158
#28	(surgery:ti,ab,kw NEAR/2 volume?:ti,ab,kw)	919



Database	Cochrane	
#29	#9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28	8600
#30	#8 OR #29	8609
#31	#5 AND #30	20
#32	#31 with Publication Year from 2013 to 2023, in Trials	19

Appendix 5.3. Inclusion and exclusion criteria

Table 40 – Inclusion and exclusion criteria for studies

Inclusion criteria	Exclusion criteria
- Published in English, French, German or Dutch - Published from 1 January 2013 to 4 August 2023 - Full text, original articles - Randomised controlled trials, non-randomised observational studies (cohort, case–control and cross-sectional studies), review articles, and audits	- Case reports, PowerPoint presentations, abstract-only studies



Appendix 5.4. Organisation of endometriosis care in Australia

The content provided in Table 41 was reviewed by Prof. Jason A. Abbott and Dr Cecilia Ng, Department of Obstetrics and Gynaecology, Women's and Children's Health, School of Clinical Medicine, UNSW Sydney, Sydney, New South Wales, Australia.

Table 41 –Organisation of endometriosis care in Australia

Country: Australia	
General information	
The health care system	The Australian health system is governed at three different levels. The federal government provides funding and support for inpatient and outpatient care but has a limited role in direct service delivery. States are responsible for (among others): public hospitals, the health care workforce, community health, mental health, regulation of private hospitals, and the location of pharmacies. The Federal and State governments fund the vast majority of healthcare in Australia. Local governments play a limited role in delivery of preventive and community health programs such as vaccination programs and health promotion activities.²⁸⁷ In Australia, there is a mixed public and private healthcare system. The national public health insurance program is called Medicare and is mainly financed through general tax revenue and provides free public hospital care and substantial coverage for physician services. Approximately half of the population purchases private health insurance, offering additional coverage for out-of-pocket fees, faster access to non-emergency services and a greater choice of providers. There are tax incentives, scaled to income, for choosing the purchase of private health insurance. Out-of-pocket expenses represent 17 percent of health care spending in 2016-2017, mainly for allied health services (e.g., physiotherapy, mental health services, dietetics, etc.) and medications not subsidised by the federal government.²⁸⁸ In Australia, patients are free to choose their healthcare provider, but general practitioners (GPs) are the main gatekeepers to specialized health care as referral to a specialist is needed to receive the Medicare subsidy. Primary and specialist care are mainly financed on a fee-for-service basis, while GPs can also receive funding from a performance-based initiative called the Practice Incentives Program. Public hospitals receive a majority of funding from the federal government based on an activity basis using diagnosis-related groups. Private hospitals are mainly financed by private health insurers and patients.²⁸⁷ The federal government encourages multidisciplinary care by funding large multidisciplinary GP clinics and Primary Health Networks. The latter are local, independent organisations (31 in total) that coordinate primary health care in their region in alignment with Local Hospital Networks.²⁸⁷ In Australia, chronic diseases are managed within a defined framework namely Chronic Disease Management (CDM) service, which is a Medicare-subsidised service coordinated by GPs to access allied health services. CMD service includes a General Practitioner Management Plan, Multidisciplinary Care Plans, and Team Care Arrangements (cf. infra).²¹⁷
Period of data collection	July - December 2023
Endometriosis	

**Country: Australia****Prevalence of endometriosis**

In a recent cross-sectional study among nearly 7 000 women aged 18-39 years, the prevalence of endometriosis was 5.4 percent, with the highest prevalence of 7.7 percent among women aged 35-39 years. The study used a community-based sample from three eastern Australia states, representative to the Australian population in terms of their age and geographic distribution, occupation, education, country of birth and relationship status. All participants were required to respond to the question 'Have you ever had a pelvic ultrasound?' Participants who responded 'yes', were then asked if they had ever been diagnosed with endometriosis.²⁸⁹

Based on a population-based cohort study among 13 508 Australian women, one in nine (11.4%) had clinically confirmed or suspected endometriosis by the age of 44.⁷⁸

Around 15 of every 1000 hospitalisations among females aged 15-44 were endometriosis-related in 2016-2017, with most endometriosis-related hospitalisations occurring among women aged 30-39.¹⁵¹

Organisation of endometriosis care**Primary health care setting**

i.e. general practitioners and allied health services

Endometriosis care in Australia is generally led by gynaecologists and monitored by GPs;²⁹⁰ to receive the Medicare subsidy patients need a GP referral to a gynaecologist.

The Australian Institute of Health and Welfare states there is a lack of data related to endometriosis and primary care. Based on the Bettering the Evaluation and Care of Health program (BEACH), some information was gathered on how general practitioners manage endometriosis, yet it was based on a small sample of general practitioners, the number of visits related to endometriosis was relatively small and data collection ceased in 2015–16.^{151, 291}

Qualitative interviews among nine Australian GPs identified several challenges with endometriosis care and points for improvement to better support GPs: increased awareness and education, the development of guidelines, recognition of endometriosis as a complex chronic condition, and increased access to centres for excellent care.²⁹²

As part of the National Action Plan for Endometriosis, which was released in 2018, several actions were undertaken to improve endometriosis care at the primary health setting:¹²⁴

- The Australian Government started funding twenty-two endometriosis and pelvic pain GP clinics through the existing Primary Health Networks, as part of the Federal Government's \$58.3 million package for endometriosis and pelvic pain.¹⁹⁷ These pelvic pain clinics are being rolled out across the country as of March 2023. They will provide multi-disciplinary care with a focus on improving the timeliness of diagnosis and promoting early access to intervention, care, treatment options, and referral services for endometriosis and pelvic pain.
- Concerning the school health setting, an expansion of the Menstrual Education Schools Program and a mobilisation of the PIPPA (Period ImPact and Pain Assessment) test in the school curriculum are mentioned within Priority Action 1, 2.1-2 of the National Action Plan.¹²⁴ Of note, the LongSTEPPE Project (Longitudinal Study of Teenagers with Endometriosis, Period and Pelvic Pain) was recently launched, recruiting 3000 teenagers to better understand the educational and management strategies in pelvic pain in Australia.²⁹³

**Country: Australia**

- A number of recommendations were made for employers to increase awareness of the prevalence and impact endometriosis has on workers and its potential impact on workplace safety.²⁹⁴ Moreover, endometriosis is a supported condition of the Disability Employment Services program, ensuring equal access to job opportunities and the support they need to succeed in the workforce.²⁹⁵

As one of the Medicare-subsidised Chronic Disease Management services, Team Care Arrangements allow individuals with endometriosis to receive up to five subsidized allied health services (e.g., pelvic physiotherapy, psychologist) per calendar year. The allied health provider supplies a report on their treatment to the referring GP after a patient's first and last service.

Individual with endometriosis are also eligible for a Mental Health Treatment Plan which can be used to access up to ten individual and ten group sessions with a mental health professional each calendar year, covering some of the cost.²⁹⁶

While several publications state that pharmacists should be included in the care pathway,¹²⁴ and that they can raise awareness of endometriosis,²⁹⁷ no specific initiatives were identified.

Secondary health care setting

i.e. local hospital with a women's health service or specialist doctors in private practice

Australian gynaecologists have historically focussed on investigations for endometriosis, offering hormones and surgery, rather than interdisciplinary care. Armour et al. argues this might be partly explained by the structure of the Medicare system, which does not adequately fund interdisciplinary care and rewards doctors for performing surgery over talking to the patients.²⁹⁸

In 2020, an international survey on diagnosis and management of endometriosis was performed among gynaecologists in Australia and New Zealand, Canada, the United States, and the United Kingdom. Overall, 36 percent of respondents from Australia and New Zealand indicated offering patients with endometriosis care in a structured multidisciplinary unit (that is, an official collaboration between gynaecology, other medical/surgical services (e.g. colorectal/general surgery, urology, chronic pain), and allied health services (e.g. physiotherapy, psychology, pharmacy).²⁹⁹

An overview of endometriosis-related hospitalisations in 2016-2017 is provided by the Australian Institute of Health and Welfare. In around 4 in 10 (44%) hospitalisations, the patient was admitted for a one day hospitalisation.¹⁵¹

The Persistent Pelvic Pain project is a real-world study (prospective observational cohort) of women referred with pain to a public gynaecology clinic who were randomised to two different clinics for routine care and followed for 36 months. Two general gynaecology units were involved: one with additional advanced endoscopic skills and the other with additional hormonal and pain management skills. Questionnaires regarding pain and quality of life, as well as medical and surgical records are analysed to explore factors influencing type of care and three-year outcomes.³⁰⁰ Interestingly, pain intensity and gynaecology unit were key predictors of undergoing laparoscopy. Patients attending a gynaecology unit with specific additional endoscopic skills were more likely to undergo surgery than women with similar symptoms who attend a unit with additional skills in medical management.³⁰¹

In November 2022, a new Medicare Benefits Scheme service was made available for pelvic MRI of endometriosis (\$25 million in funding). This MRI scan can be requested by a specialist or consultant physician and applies to patients who experience sub-fertility or deep endometriosis.³⁰²

Tertiary health care setting

Numerous tertiary gynaecology centres offer endometriosis care in Australia, and some of these centres are self-proclaimed endometriosis centers.^{fff} There are currently no licensing standards for officially recognised endometriosis centres in the tertiary

^{fff} For instance: <https://www.epworth.org.au/our-services/endometriosis-centre>

**Country: Australia**

i.e. hospitals with tertiary (including sub-specialist) level expertise

health care setting (cf. section on reference centers). This is despite a recommendation in the National Action Plan of 2018 to identify these tertiary referral centres.¹²⁴

The majority of these tertiary gynaecology centers use referral guidelines for primary/secondary care providers.⁹⁹⁹⁹ For some gynaecological conditions, a comprehensive referral including specific investigations is required. In case of referral for (suspicion of) endometriosis, a pelvic ultrasound and a pap smear are often required.

Care pathway for endometriosis

Recommendations on when patients with endometriosis should be referred from primary care to gynaecological specialist services are provided in the clinical guideline of The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).¹⁹⁸ Within the frame of the National Action Plan for Endometriosis (Priority Action 1 - point 3.1) it is provided to develop a more comprehensive flow diagram to map the pathways for individuals with endometriosis or chronic pelvic pain through the healthcare system.

Initiatives to install/enhance multidisciplinary care

No information retrieved.

Proximity of care

No information retrieved.

Access to care

Several qualitative studies were performed in Australia to evaluate the perception of endometriosis care among both patients and health care professionals:

- A comparison of patient and practitioner perceptions of endometriosis care in the Australian primary healthcare setting is provided in Rowe et al. Patients reported that healthcare providers lack essential knowledge and provide inconsistent advice, while treatments are unsuccessful and have adverse side-effects. Health professionals acknowledged limitations in expertise and expressed frustration with providing care for this complex, chronic condition.¹³⁵
- Based on an online survey performed in 2019, only 24 percent of 532 women with self-reported endometriosis were satisfied with the management of their endometriosis.¹²⁵
- Another survey among 620 women with surgically diagnosed endometriosis reported that the majority of participants experienced symptoms including chronic pelvic pain, dysmenorrhea, and dyspareunia despite surgical, hormonal, and pain management treatment. Respondents consulted an average of three different health practitioner specialties in the last year for their endometriosis, and they reported the need for a multidisciplinary approach. Only a minority of participants had a Chronic Disease Management Plan, which was associated with a higher use of hormonal treatment and the prescription of pain medication.⁹

⁹⁹⁹⁹

Some examples of such referral guidelines: https://health-services.mercyhealth.com.au/wp-content/uploads/sites/31/2017/08/Gynaecology_-Referralguidelines_V2.0.pdf; <https://cdn.wchn.sa.gov.au/downloads/WCH/professionals/referral-guidelines/Gynaecology-Referral-Guidelines.pdf>; <https://www.thewomens.org.au/health-professionals/for-gps/referrals/womens-health-and-gynaecology-referrals> (no systematic search was performed)

**Country: Australia**

- Young et al. reported on the clinicians' perceptions of women's experiences of endometriosis and of psychosocial care for endometriosis. Among other findings, most clinicians assessed themselves as not adequately trained to understand and provide adequate care for psychosocial aspects of endometriosis.³⁰³

In 2011, the Pelvic Pain Report was published by the Pelvic Pain Steering Committee to reveal the extent of pelvic pain in Australia and recommend its inclusion in health policies and programs. It includes an extensive list of issues and barriers in pelvic pain care identified by health professionals, patients, and researchers.³⁰⁴

Other surveys report on allied health and complementary therapy usage, or self-management strategies in Australian women with endometriosis. One study found that women with endometriosis have high rates of allied health (the most commonly accessed were physiotherapists and mental health workers) and complementary therapy usage, associated with a high out of pocket cost.[ref] Furthermore, a positive association was found between income and educational levels on the one hand and the use of allied health and complementary therapy, suggesting inequitable access to these services.³⁰⁵ Self-management strategies such as heat, meditation or breathing exercises are common among Australian women with endometriosis, while women using cannabis reported the highest self-rated effectiveness in pain reduction.³⁰⁶

An average diagnostic delay of 6.4 years was reported by 620 Australian respondents using a cross sectional online survey.⁹ In another survey, an average delay of eight years from symptom onset was described. Three years of this delay were attributable to the delay between symptom onset and seeking medical care, and the remaining five years between an initial doctor visit and surgical diagnosis of endometriosis.³⁰⁷

Any other valuable information

The per person cost of endometriosis was estimated at around USD 20 000 per year among study participants drawn from advocacy groups, the majority of costs was due to productivity loss.⁸⁸

Reference centres for endometriosis**General info**

Distinction should be made between reference centres in primary care which are being implemented (endometriosis and pelvic pain clinics) and those in tertiary care (centres of expertise):

Primary care - endometriosis and pelvic pain clinics:

As of March 2023, twenty endometriosis and pelvic pain GP clinics are being rolled out through the existing Primary Health Networks,¹⁹⁷ at least one clinic in every state and a mix of regional and metropolitan locations. Two additional clinics were announced in September 2023.³⁰⁸

Tertiary care - centres of expertise:

Reference centres in the tertiary care setting are self-proclaimed, although the establishment of funded centres of excellence has been proposed in the National Action Plan for Endometriosis (Priority Action 2, 1.1-2.1).¹²⁴ Currently no licensing standards or frameworks exist.(Confirmed by reviewer)

Who is referred to reference centres?**Primary care - endometriosis and pelvic pain clinics:**

Patients can directly book an appointment.

Tertiary care - centres of expertise:

**Country: Australia**

Patients may book directly for an appointment, although most jurisdictions recommend a referral from primary care due to an additional payment. Patients that present to an emergency department can be directly referred to a hospital appointment without a general practice referral. *(Personal communication with reviewer)*

Licensing standards**Primary care - endometriosis and pelvic pain clinics:**

There was a selection of existing GP practices specialising in women's health (max. three per Primary Health Network) that met the majority of predefined selection criteria, which include (among others):³⁰⁹

- Demonstration of scalability to meet potential increase in demand
- Geographical reach
- Provision of different payment methods including bulk billing
- Core services provided (GP, practice nurse, allied health practitioners (e.g., mental health services, occupational therapy, physiotherapy, and psychology), community networks etc).
- Additional services (not mandatory) such as infertility support
- Active referral pathways to dedicated women's health services and tertiary care services
- Education and training of health care professionals
- Infrastructure

Tertiary care - centres of expertise:

No information retrieved.

Quality assurance**Primary care - endometriosis and pelvic pain clinics:**

An evaluation of the success of the GP clinics will start in 2023 and be completed within the next 2 years.¹⁹⁷

Tertiary care - centres of expertise:

No information retrieved.

Dedicated funding of reference centres**Primary care - endometriosis and pelvic pain clinics:**

The Clinics are part of the Federal Government's \$58.3 million package for endometriosis and pelvic pain, announced in the 2022-23 Budget. Each clinic is supported by more than \$700 000 in funding over four years. This funding may be used for a wide range of services including but not limited to advanced training qualifications, further study, additional practice staff (e.g., allied health, nurse navigators), enhanced referral pathways with local providers, equipment purchase.³⁰⁹

Tertiary care - centres of expertise:

No information retrieved.

Legal framework**Primary care - endometriosis and pelvic pain clinics:**

No information retrieved.

Tertiary care - centres of expertise:

No information retrieved.



Country: Australia

Is there a liaison between reference centres and the primary and secondary level?

Primary care - endometriosis and pelvic pain clinics:

Having active referral pathways to dedicated women's health services and tertiary care services, including, but not limited to specialist gynaecological, radiological, surgical, endocrinological, multidisciplinary pain management, fertility, mentor support and psychological support services, is one of the licensing standards.³⁰⁹

Furthermore, a collaboration network has been established between the endometriosis and pelvic pain clinics funded by the new initiative.³¹⁰

Tertiary care - centres of expertise:

No information retrieved.

Public reporting/Published evaluation of the reference centres?

Primary care - endometriosis and pelvic pain clinics:

There are no results available yet, nor information on the outcomes that will be assessed.

Tertiary care - centres of expertise:

No information retrieved.

Any other valuable information

No information retrieved.

Recognition of endometriosis as a chronic condition

Is endometriosis recognised as a chronic condition?

In Australia there is no accepted standard definition for chronic conditions.

The definition of a chronic condition put forward by the Australian government is 'a medical condition that has been or is likely to be present for six months or longer'. There is no list of eligible conditions for chronic disease management (CDM) services, whether a patient is eligible for a CDM service is essentially a matter for the GP to determine.²¹⁷

In the 2018 National Action Plan, one of the key priorities is to ensure endometriosis is recognised as a chronic condition by all health practitioners. Use of existing chronic disease management mechanisms such as GP Management Plans and Team Care Arrangements can be considered to ensure appropriate care.¹²⁴

Licensing standards

GPs can check a patient's eligibility for a Chronic Disease Management Plan by using an online items checker. The access for this eligibility check is secured for Australian healthcare providers, we were not able to run through the procedure.³¹¹ If a patient experiences symptoms for at least six months, e.g. chronic pelvic pain, the patient would be eligible for a CDMP. Furthermore, a specialist agreement to the plan is required for payment to be made to the general practitioner. (*Personal communication with reviewer*)

How is the recognition installed?

Chronic Disease Management (CDM) services are Medicare-subsidised services provided by GPs. A review of a patient's CDM service is recommended to occur every 6 months, or as clinically necessary.³¹¹

Consequences for patients

The beforementioned Chronic Disease Management Plans and Team Care Arrangements can be provided by GPs to individuals with endometriosis. Team Care Arrangements allow to receive up to five subsidized allied health sessions per calendar year (e.g., mental health services, occupational therapy, physiotherapy, and psychology).



Country: Australia	
	Other available support for Australian patients with a chronic illness includes financial support for students, and support for independent living. The full range of support and benefits varies between each state and territory. ^{312, 313}
Consequences for the health care setting	No information retrieved.
Funding	Chronic Disease Management (CDM) services are Medicare-subsidised services.
Evaluation of endometriosis being recognised as a chronic condition	No information retrieved.
Any other valuable information	As the GP is the coordinator of the plan and thus the gateway to accessing allied health services, they require a knowledge of available qualified practitioners. Furthermore, the limited number of funded sessions (maximum of five) can be inadequate for improving health outcomes, and the subsidy provided is often 50% or less of the total cost. ²⁹⁸ Despite the availability of a Chronic Disease Management Plan (CDMP), a cross-sectional survey among 620 Australian women indicated that only 15% of endometriosis patients indicated having such a CDMP. ⁹
Endometriosis registry	
Is there an endometriosis registry?	Yes, as part of the National Endometriosis Clinical and Scientific Trials (NECST) network which was established in 2018 by a collaborative group of clinicians, allied healthcare providers, researchers, and endometriosis patient advocates. The Registry went live in December 2020 and has been piloted at sites in New South Wales to test the registry infrastructure. ²¹³
Who is in charge?	The NECST Registry was initially administered and managed by Jean Hailes for Women's Health, a national non-profit organisation, but is now under administration and management at the University of New South Wales (UNSW, Sydney). <i>(Personal communication with reviewer)</i>
Legal framework	No information retrieved.
Funding	The Australian Government's Medical Research Future Fund (MRFF) and the Australian Government's Department of Health and Aged Care.
Criteria	Australian residents aged over 18 with surgically confirmed or clinically suspected endometriosis and/or adenomyosis. Participants should speak English. ²¹³
Coverage	Recruitment is possible from hospitals, specialist private clinics, and the general community via social media. Clinicians and/or research team members have to assess the eligibility of patients for the registry. In a first instance high-volume, public tertiary hospitals have been recruited. ²¹³
Data collected?	Participants are asked to fill in a baseline survey (30-40 minutes) and then surveys (15-minutes) six and twelve months after the first survey, and then every year. Data include demographics, overall quality of life survey using EQ-5D, endometriosis quality of life survey using the EHP-30. Doctors and research staff can add results and clinical data (e.g., imaging records, surgical records etc.). A complete overview of the data collection methods is provided in the publicly available data dictionary in the supplementary materials of the publication of Ng et al. ²¹³



Country: Australia	
	Linking to other databases is provided: hospital admission data, the Medicare Benefits Schedule, the Pharmaceutical Benefit Scheme, the Australia and New Zealand Assisted Reproduction Database.
Results	Studies based on NECST Registry data will be published in peer-reviewed journals. Furthermore, the investigators will provide an Annual Progress Report to ethics and funding organisations. In November 2022, Ng et al. presented a brief overview of clinical presentation measurements of the first 890 participants.²¹⁶ Publishing of further results of the participant cohort and their associated PROMs data is planned. <i>(Personal communication with reviewer)</i> The protocol for establishing the NECST Registry was published in April 2023.²¹³
Any other valuable information	https://www.unsw.edu.au/research/necstnetwork/registry
Guidelines and quality indicators	
Guidelines	The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) published Australia's first clinical guideline on the diagnosis and management of endometriosis in 2021.¹⁹⁸ The guideline was funded by the Australian government and is based on National Institute for Health and Care Excellence (NICE) guidance [NG73] (2017) Endometriosis: diagnosis and management.² In a recent systematic review of clinical practice guidelines, the RANZCOG guideline was classified as "excellent" alongside the NICE and ESHRE endometriosis guidelines.³¹⁴ The Australian government has recently funded RANZCOG to create a living guideline to include new and ongoing research into the diagnosis and management of endometriosis.³¹⁵ A first review will be published in 2024. <i>(Personal communication with reviewer)</i> RANZCOG also made a proposal to lead a state-funded guideline dissemination and implementation program. The 3-year proposal aligns with several priority actions of the National Action Plan for Endometriosis.³¹⁶
Quality indicators	No quality indicators were identified.
Care pathway for endometriosis	The RANZCOG guideline includes consensus-based recommendations on when people with endometriosis should be referred from primary care to gynaecological specialist services.
Any other valuable information	https://ranzcof.edu.au/resources/endometriosis-clinical-practice-guideline/
National action plan for endometriosis	
National action plan for endometriosis	The five-year National Action Plan for Endometriosis was launched in 2018, from a partnership between government, endometriosis experts and advocacy groups. The plan is aligned to the goals of the National Strategic Framework for Chronic Conditions, which was published by the Australian Health Ministers' Advisory Council in 2017. ¹²⁴
Key actions	The key directions of The National Action Plan are: Awareness and education: Actions related to understanding across educational, professional and community settings, as well as within the healthcare sector. Clinical management and care: Actions related to diagnosis, treatment options, care pathways and clinical guidelines as well as the provision of ongoing support for people living with endometriosis. Research: Actions related to research, including tailoring of international priorities for the domestic context.

**Country: Australia****Evaluation**

A short progress report has been published in February 2023, with an overview of different activities in the three key domains. A five-year assessment of the National Action Plan will be performed by the Department of Health and Aged Care in the second half of 2023.³¹⁵

There are six proposed criteria for this five-year review of progress:

- Development and dissemination of a national guideline?
- Has access to appropriate healthcare improved?
- Have school menstrual education programs been implemented?
- Do healthcare professionals show a base-level increase in understanding of endometriosis?
- Development of care pathways, from first consultation through to post-operative care?
- Significant expansion of the domestic research program?

We did not identify specific methods to measure some of these criteria, for instance on access of care, or increase in knowledge about endometriosis among healthcare professionals. In other words, there are no formal performance indicators for what is deemed 'success' in the National Action Plan. (*Personal communication with reviewer*)

Several progress assessments are provided in commentaries by national endometriosis experts.^{123, 298} Overall, the National Action Plan is considered an important milestone for endometriosis care but it is also acknowledged that not all goals have been achieved.

Funding

As of February 2023, the Australian Government has released approximately \$87 million in funding. An overview of the fundings are publicly available in the Endometriosis Progress Report.³¹⁵

Any other valuable information

Utilisation of accreditation guidelines for advanced laparoscopic surgery, which are already developed by the Australasian Gynaecological Endoscopy and Surgery Society (AGES) and RANZCOG. These guidelines include American Society for Reproductive Medicine (ASRM) stages for endometriosis to determine different levels of procedures.³¹⁷

Patient Reported Outcomes Measures (PROMs) are proposed to measure the effectiveness of the National Action Plan in meeting its objectives.

Training about endometriosis**Primary care professionals**

The RANZCOG Endometriosis eLearning Module is a free self-directed online module for health professionals.²²⁴

RANZCOG also developed the Raising Awareness Tool for Endometriosis (RATE), a quick-to-use electronic resource for primary health care professionals and their patients to help identify endometriosis.²³³

Medical specialists involved in endometriosis care

In Australia, gynaecologists can apply for the RANZCOG-accredited Certification in Obstetrical and Gynaecological Ultrasound (COGU) fellowship, becoming experts in this specific area.³¹⁸ In 2020, the results of an international survey on diagnosis and management of endometriosis were published, indicating that 12 percent of gynaecologists working in Australia and New Zealand had followed a supplementary ultrasound training.²⁹⁹

**Country: Australia**

The Australasian Gynaecological Endoscopy and Surgery (AGES) Society provides an Accredited Training Program (AATP). This is a two-year training program in advanced gynaecological endoscopy to facilitate endoscopic training in Australia and New Zealand. The AATP is a result of over a decade long collaboration between AGES, RANZCOG, leading clinicians, trainees and researchers throughout Australia and New Zealand, and provides a template for the standardisation of training in advanced endoscopic surgery.³¹⁹

Any other valuable information

No information retrieved.

Awareness about menstrual health and endometriosis**Brief overview**

A variety of educational programs have been developed to improve menstrual health education and awareness of endometriosis in the general public:

- Period Talk³²⁰
- PEPP Talk²³⁴
- QENDO Schools Program³²¹
- Endometriosis Australia Webinars³²²

EndoZone is a National Endometriosis Digital Health Platform co-created by researchers, clinicians, and the endometriosis community. It is an evidence-based platform aiming at the general public, persons affected by endometriosis, and health care professionals.³²³

Other initiatives can be found in the Progress Report of the National Action Plan.³¹⁵

Any other valuable information

No information retrieved.

Any remaining thoughts, suggestions, comments, ...

An online survey among Australian people with endometriosis and their family members, showed that effective treatment and the cause of endometriosis are the most important research priority areas.³²⁴

In April 2019, the Department of Health launched the National Women's Health Strategy 2020 to 2030.³²⁵

By including conditions such as polycystic ovary syndrome, adenomyosis, pelvic inflammatory disease and chronic pelvic and period pain, the focus is not only put on endometriosis.



Appendix 5.5. Organisation of endometriosis care in Denmark

The content provided in Table 42 was reviewed by Dorthe Hartwell, Head of the Endometriosis Clinic, Rigshospitalet in Copenhagen.

Table 42 – Organisation of endometriosis care in Denmark

Country: Denmark	
General information	
The health care system	Since 2007, the Danish healthcare system can be described in three administrative levels.³²⁶ 1) The state: responsible for legislation, national guidelines and health financing through the Ministry of health 2) The regions (n=5): responsible for the delivery of primary and hospital-based care 3) The municipalities (n=98): responsible for a range of welfare services (e.g. school health, child dental treatment, home care, primary disease prevention, rehabilitation) The Danish health system is financed by taxes, general tax revenue at state level and to a lesser extent municipal income tax.³²⁷ The central government allocates grants to regions and municipalities based on demographics and activity levels. All Danish residents are automatically covered by the tax-funded national health system, which covers most of the costs of medical services. The extensive public coverage for medical services in Denmark results in few unmet needs. In 2019, less than 2 % of the population reported unmet needs for medical care due to cost, distance or waiting times in 2019. The Danish health system uses a higher public share of health spending (83%) than the EU average (75%) in 2019.³²⁷ All Danish citizens have free access to the health care system with direct access to a general practitioner (GP).³²⁷ The GP acts as a gatekeeper, providing primary care and access to hospital/specialist care.³²⁷ The hospital care in Denmark can be categorised in two levels, the general or the specialised level.³²⁶ On the specialised level, two types of treatment can be distinguished: a regional treatment function or a highly specialised treatment function. A regional function is placed at 1–3 locations in a region, and collaboration among the units is required. Treatment at highly specialized level is typically placed at 1–3 locations in the country. Hence, specialized treatment has been centralized at a few hospitals, in some cases only one hospital.³²⁶
Period of data collection	July – December 2023
Endometriosis in Denmark	
Prevalence of endometriosis	A registry-based cohort study, which included all women aged 15–55 living in Denmark from 1990–2017, suggested a prevalence of hospital-diagnosed endometriosis of 1.63% (in 2017). ³²⁸ The study pointed to an overall increase in incidence during the study period and to significant regional differences. ³²⁸
Organisation of endometriosis care	



Country: Denmark

Primary health care setting	A GP is the first point of contact for patients, providing initial assessment and/or treatment. ³²⁶ A GP referral is required for hospital care or specialist consultation and are able to refer a patient directly to a reference centre for endometriosis care (cf. Tertiary care). ³²⁹
Secondary health care setting	Patients are referred to medical specialists (e.g. gynaecologist) in private practices or hospitals, both of which are covered by the public health insurance. ³²⁷ In 2002, it was decided to centralise the treatment of advanced endometriosis (cf. section reference centres). ¹⁵⁸ Hospital referral is required for a surgically verified diagnosis of endometriosis. ³²⁶
Tertiary health care setting	Yes (cf. Infra – <i>Reference centres for endometriosis care</i>)
Care pathway for endometriosis	No information found
Initiatives to install/enhance multidisciplinary care	The Danish authorities decided in 2002 to centralise advanced endometriosis care in two centres with specific expertise in endometriosis care and (dedicated) multidisciplinary teams. ¹⁵⁸ Additionally, the Danish Endometriosis Patients' Association was established and started working nation-wide to inform its members at regional meetings about the new referral options and raise awareness. ¹⁵⁸
Proximity of care	In 2015, significant structural differences were noted between Eastern and Western Denmark, with Copenhagen having seven times as many gynaecological private specialists per 100 000 inhabitants than northern Jutland.³²⁸ No specific information found on proximity of care in tertiary care for endometriosis (cf. reference centres). However a central guiding principle in the Danish Health act states the following on proximity of care of specialised hospital services:²⁰⁸ <i>“Another premise is to ensure that citizens receive uniform, high-quality treatment across the country. This is ensured, for example, through planning of where and on what basis various services can be performed. If there is a conflict between delivering high-quality healthcare and delivering health-care close to where the patient lives, the consideration of high-quality healthcare is prioritised.”</i> The approval of specialised services by the Danish Health and Medicines Authority (DHMA) thus takes into account, to a certain extent, the physical location of the hospital.²⁰⁸ In 2002, it was estimated that a maximum of 100-200 patients would need to be referred to a specialised centre. To ensure a reasonable volume and surgical routine it was considered appropriate to establish two centres. Therefore, a centre was established in western Denmark (Aarhus, the second-largest city in Denmark) and one in eastern Denmark (in Copenhagen). <i>At that time, the laparoscopic skills among gynecologists in Denmark were still limited, and the choice fell on two departments that had surgeons capable of handling the task. Later, another center was established in Odense (Denmark's third-largest city), which has a formalized collaboration with the specialized centre of Copenhagen. Geographically, the three centers are well distributed in Denmark, and the travel time to any of the centers is short for most patients, usually not exceeding 2-3 hours from the farthest locations.</i> (Personal communication with reviewer)
Access to care	The centralisation of care along with efforts of the Danish Endometriosis Patients Association to raise awareness have doubled the number of endometriosis patients referred to Danish hospitals during the period 1997- 2005. ³³⁰

**Country: Denmark**

Despite these efforts Danish endometriosis patients feel neglected and not taken seriously by their doctor.³³¹ They mention that it's hard to receive a definitive diagnosis.³³¹

Any other valuable information

Patients diagnosed with endometriosis had a significantly higher use of primary and secondary healthcare 10 years prior to diagnosis compared to women without diagnosed endometriosis.³³²

Reference centres for endometriosis**General info**

Two national referral centres are officially recognised: *Aarhus University Hospital* (Skejby) and *Rigshospitalet* (Copenhagen). They are authorized and specialized in the diagnosis and treatment of patients with advanced endometriosis.

- **Aarhus University Hospital**²⁰¹
 - o A multidisciplinary team with four specialized nurses and four senior doctors, close collaboration with other specialists (urologists, gastro- and plastic surgeons).
 - o A large patient volume for both medical and surgical treatment of endometriosis.
 - o The largest referral center for advanced endometriosis in Scandinavia.
 - o Part of a laparoscopic training unit for both pre- and postgraduates.
 - o Members of the endometriosis team are trained in ultrasound diagnosis of rectovaginal endometriosis as a first line approach in the outpatient's clinic.
 - o The only clinic in Northern Europe subspecialised in endometriosis with affection of the lumbo-sacral plexus.
- **Rigshospitalet, Copenhagen**^{201, 202}
 - o A multidisciplinary team of medical specialists and nurses offer medical as well as surgical treatment (e.g. laparoscopy, robot surgery).
 - o In advanced cases close collaboration with gastro surgeons and gynecologists who have special skills in treating rectovaginal and intestinal endometriosis. As well as experts in pathology, medical oncology and radiotherapy.
 - o 6 000 total admissions a year (all diseases).
 - o 2 400 surgical procedures a year (all diseases).
 - o 400 newly referred patients per year.
 - o The department of gynaecology has a focus on research, medical education and surgical training programs in close collaboration with national and international (research) groups.

Who is referred to reference centres?

All women with a suspicion of endometriosis or a diagnosis of endometriosis can be referred a national reference centre by their primary care professional.³²⁹ However, these national reference centres mainly focus on advanced endometriosis, patients who do not present with advanced endometriosis are referred back to primary care or specialist care (e.g. gynaecologist) follow-up outside of the reference centres.³³³



Country: Denmark

	Because of this focus on advanced endometriosis, the treatment of advanced endometriosis outside of these two reference centres has nearly vanished.³³⁰ The number of patients who were treated for endometriosis of the rectovaginal septum more than tripled between 2000 and 2005. In 2005, 2/3 of these patients were treated at the two Danish centres of excellence. The other 1/3 of patients with endometriosis in the rectovaginal septum are still treated outside the centres with special surgical skills in endometriosis. The number of patients treated for ovarian endometriosis has been relatively stable over the years.³³⁰
Licensing standards	No specific national licensing standards on endometriosis were found, besides the formal, national guidelines from the DHMA for centralised treatment of advanced disease.^{208, 334} Hospitals approved to perform a specialised service (e.g. endometriosis) must comply with the requirements specified in the relevant speciality guidelines (e.g. requirements for collaboration with other specialities, formal collaborations) published by the DHMA, the specific approval document, the overall prerequisites (e.g. location, public service obligation) and requirements for the performance of specialised services (e.g. capacity, expertise, qualifications).²⁰⁸ An update of this guideline is expected soon. <i>(personal communication with reviewer)</i>
Quality assurance	The DHMA defines the requirements for specialised hospital services at regional and private hospitals, and approves individual hospitals to provide specific specialised services. The DHMA has the statutory authority to establish/discontinue specialised services and to grant/withdraw approvals for the performance of specialised services.²⁰⁸ The DHMA is responsible for performing regular reviews (e.g. annual status report) and monitoring on quality and volume of activity, to ensure that the current specialised hospital services is adequate.²⁰⁸ No specific quality assurance/evaluation found for endometriosis care.
Dedicated funding of reference centres	Funding of these reference centres and endometriosis treatment is organised within the public health care system. ²⁰⁸
Legal framework	The formal guidelines from the DHMA on centralised treatment of advanced disease, stipulate that advanced endometriosis care can only be offered in the two appointed reference centres (2001). ^{158, 208}
Is there a liaison between reference centres and the primary and secondary level?	GPs are legally allowed to refer patients directly to reference centres. ³²⁶
Public reporting/Published evaluation of the reference centres?	No results of quality/care/... are published publicly, besides the research output.
Any other valuable information	In addition to diagnosis, medical treatment and (advanced) surgery, both national centres play a leading role in education and research activities.²⁰¹ They also provide guidance and support to diagnosed and treated patients (ex. counseling, group-based discussion/teaching (Endo life), conversation process with nurse (guided self-decision) and auditorium teaching (Endoviden)).^{201, 202} In 2005, the risk for laparotomy in the two centres of excellence was 6% in comparison to 14.4% in other Danish hospitals.³³⁰

**Country: Denmark**

Currently, the highly specialized centers are subject to evaluation regarding professional skills and organization to maintain the function of the Health Authority. We are monitored by the hospital for serious complications, especially for procedures involving colorectal surgery. *(Personal communication with reviewer)*

Over the years, we can observe a growing and larger proportion of surgeries, where endometriosis is the primary diagnosis being performed at the specialized centers, exceeding 60% in 2018. *(Personal communication with reviewer)*

Recognition of endometriosis as a chronic condition

Is endometriosis recognised as a chronic condition? *No, there is no official recognition by the health authorities in Denmark.*

Licensing standards**How is the recognition installed?****Consequences for patients**

Endometriosis patients have several rights once they receive a diagnosis of endometriosis. These patient rights include:

Section 56 of the Sickness Benefit Act (§56 agreement)

- This agreement allows individuals with an increased risk of sick leave from work due to long-term or chronic illness, to enter into an agreement with their employer and the municipality.³³⁵ This agreement allows the employer to reduce their expenses during your sick leave by receiving a sick pay reimbursement from the first day of absence.³³⁵
- Only applicable if endometriosis results in sick leave of at least 10 days per year.³³⁵

Flexible jobs

- These jobs are granted to people with significant and reduced earning capacity who are not fit to have a job in ordinary conditions.³³⁶
- The job center makes a decision on the right of flexible work based on a recommendation from the rehabilitation team. A flexible job is temporary and the municipality must assess the status of an employee after 4.5 years.³³⁶
- The employees' limited working capacity is taken into account and the municipality pays a subsidy to the salary. This subsidy compensates for the reduced working capacity.³³⁶

Early retirement

- Persons with a significant and permanent reduced ability to work may be granted early retirement.³³⁷

Disability supplement

- The supplement is given when your functional impairment gives you significant limitations in your ability to take on a student job alongside the education due to e.g. pain or fatigue.³³⁸

Supplements for birth control pills and hormonal spirals and diogenest

**Country: Denmark**

- Endometriosis patients have the option of applying for supplements for birth control and hormonal spirals. Through contact with a GP, endometriosis patients are able to apply for a "single supplement", the doctor must state that the birth control pills are used for medical purposes to treat endometriosis.²²¹
- Endometriosis patients who can't tolerate a certain type of birth control pill, can apply for "increased supplement".²²²

Consequences for the health care setting**Funding****Evaluation of endometriosis being recognised as a chronic condition****Any other valuable information****Endometriosis registry**

Is there an endometriosis registry? *Some years ago work was done in order to create a registry, but no funding was found and it was never established. (Personal communication with reviewer)*

Who is in charge?**Legal framework****Funding****Criteria****Coverage****Data collected?****Results****Any other valuable information**

In Denmark endometriosis research often uses (hospital) data from the Danish National Patient Registry (DNPR), which contains information on all public & private hospital contacts and diagnoses. Cases are identified with a first-time recorded hospital based diagnosis of endometriosis (ICD-8 codes 62530 and 62532–62539 from 1977 to 1994 and ICD-10 codes DN801–809 from 1994 onwards).³²⁸ In 2003, it became compulsory for private hospitals and private outpatient specialty clinics to report to the DNPR, still excluding private practice specialists and GPs.³³⁹ Private practice specialists are only obliged to report activities that are not covered by the health insurance scheme.³³⁹

Several databases/registries are linked to the DNPR, however no specific endometriosis registries.³³⁹ Data from the DNPR can be linked with data from the National Pathology Data bank, which contains information on pathoanatomical tests, to confirm a histologically verified endometriosis diagnosis.³²⁸

In Denmark, a hysterectomy database that continuously records complications related to hysterectomy is kept, this database includes cases where endometriosis is the primary indication. (personal communication with reviewer)



Country: Denmark	
Guidelines and quality indicators	
Guidelines	The Danish Society for Obstetrics and Gynaecology (DSOG) developed three guidelines on endometriosis. ³⁴⁰ These include: - Endometriosis, diagnostics and investigation (2022) - Endometriosis, treatment of peritoneal endometriosis (2013) - Treatment of endometriomas (2017) - o In women with pregnancy desire - o In women without a current pregnancy desire
Quality indicators	No information found
Care pathway for endometriosis	No information found
Any other valuable information	<i>There exist regional guidelines (at least for the Capital Region) for treatment of endometriosis at the local hospital and guidelines for general practitioners regarding the investigation, initial treatment, and potential further referral of patients suspected of having endometriosis. (personal communication with reviewer)</i>
National action plan on endometriosis	
National action plan on endometriosis	No national action plan on endometriosis has been installed so far. Yet, hearings were held in the parliament at 25 may 2023 to <i>convince parliament to create one.</i> ³⁴¹
Key actions	Not applicable
Evaluation	Not applicable
Funding	Not applicable
Any other valuable information	
Training about endometriosis	
Training on endometriosis during the professional curriculum of primary care professionals	In the master programme of medicine a course on gynaecology and obstetrics is included: theory and clinical practice (4 weeks). There is no Danish postgraduate educational program in gynaecological care, so nursing staff members are not formally specialized. ³⁴²
Training on endometriosis during the continuing medical education of primary care professionals	The Danish endometriosis patient organisation and national reference centres provide courses and/or information for primary care workers via their websites and members, but no structural (national) program is in place. ²²⁵
Other initiatives to improve the knowledge on endometriosis among primary care professionals	Professional health care workers who need advice, guidance or extra information about endometriosis have the opportunity to contact specialist(s) at an endometriosis reference centre by telephone (ex. Endofonen). ^{225, 226}


Country: Denmark
Training on endometriosis during the professional curriculum of medical specialists involved in endometriosis care

There is an expert educational program (3 years) for gynaecologists in endometriosis. This course exists of clinical work at a reference centre, scientific meetings, courses and research. Medical specialists participating in this expert education program are also sent abroad for 3 months to ensure their surgical level and collaborate internationally within the field of endometriosis.

Training on endometriosis during the continuing medical education of medical specialists (involved in endometriosis care)

The national reference centres also organize educational and courses of health professionals from beginner to expert levels.

Other initiatives to improve the knowledge on endometriosis among medical specialists

The Nordic Federation of Societies of Obstetrics and Gynaecology (NFOG) facilitates visits to centres of special skills/interest throughout the Nordic countries, and both Danish reference centres for endometriosis are candidates.²⁰¹ They also offer additional trainings for experts in the Nordic countries.³⁴³

Any other valuable information

Medical specialist education in gynaecology and obstetrics is updated/reviewed annually. In a last update the education around gynaecological echography has been more emphasized, as mentioned in the latest edition of the guideline on diagnosis and investigation of endometriosis.³⁴⁰

Awareness about menstrual health and endometriosis
Education on menstrual health

Sexual education in Denmark covers the topic of menstruation and is compulsory, the national curriculum targets the age group of pupils in primary and lower secondary school (ages 6-16 years).

The patient endometriosis organisation provides teachers with extra information, conversation cards & videos for teachers.³⁴⁴

Education on endometriosis

Most educational material, information (written, webinars, social media,...), conversation cards (developed tool) for teachers on endometriosis is provided by patient organisations or private initiatives.^{344, 345}

Volunteers from the Danish Endometriosis' association help to guide endometriosis patients with their journey and can be contacted through the association, if needed. There is no structural strategy to increase the knowledge & awareness about endometriosis in schools.

Awareness campaigns on endometriosis (laymen)

The Danish Endometriosis Patients' Association organised annual regional meetings at one of the reference centres. Since 2022 there are 5 regional meetings spread across the country.³⁴⁶

Other initiatives are set-up to improve awareness such as "the lady walk" (www.ladywalk.dk), "endometriosis awareness month",...

Awareness campaigns on endometriosis (health professionals)
Any other valuable information

Interesting research initiative from Denmark: FEMale (Finding Endometriosis using Machine Learning) project

**Country: Denmark**

Research project, funded by horizon 2020, to help improve diagnosis of endometriosis in the future. FEMale aims to develop a platform that uses algorithms to detect, diagnose and treat people with endometriosis, in collaboration with their health-care providers.

**Any remaining thoughts, suggestions,
comments, ...**



Appendix 5.6. Organisation of endometriosis care in France

The content provided in Table 43 was reviewed by Dr Christine Revel-Delhom, project leader at the Haute Autorité de Santé, Paris (France).

Table 43 – Organisation of endometriosis care in France

Country: France	
General information	
The health care system	The French health care system is organised around statutory health insurance, which covers 96% of the population. There is an official list of services, medicines, equipment and devices covered by the statutory health insurance. The list includes a large basket of benefits common to all residents of France.³⁴⁷ In 2020, France spent 12% of its GDP on health care.³⁴⁸ Revenues for healthcare come from social security contributions, taxes (mainly income taxes) and a small contribution from the national government. In 2019, health expenditure was mainly financed by statutory health insurance (71%) and to a lesser extent by private complementary health insurance (14%), out-of-pocket payments (9%) and the state (6%). In order to reduce the financial burden of out-of-pocket payments, protection mechanisms have been put in place for patients with a very low income or with a chronic condition which is included in the list of long-term conditions (<i>'Affection de longue durée', ALD</i>), allowing them to be exempted from paying the co-payment.³⁴⁷ Gatekeeping is not compulsory in France. However, since 2004, in order to receive the maximum reimbursement rate for a consultation with a specialist, the patient must be referred by a referring physician. The referring doctor (<i>'Médecin Référent'</i>) is a general practitioner or a specialist chosen by the patient. This reimbursement rule is not applied for patients under 16, for all pregnancy-related care and for access to certain specialists, including gynaecologists.³⁴⁷ The first year of training is the same for midwives and medical doctors. Access to the second year is restricted by competitive examination. The total duration of midwifery training is 5 years. Medical training lasts 6 years, supplemented by 3 years of training in general medicine, 8 semesters in medical gynaecology and 12 semesters in gynaecology and obstetrics.³⁴⁹ Health professionals working in public hospitals are salaried civil servants, while those working in the outpatient sector or in private hospitals are paid on a fee-for-service basis.³⁴⁷
Period of data collection	July - December 2023
Endometriosis in France	
Epidemiology of endometriosis	A study analysed the incidence of hospitalised endometriosis in France from 2011 to 2017.³⁵⁰ The authors identified the cases reported in the French national hospital discharge databases by using ICD-10 codes for endometriosis and classified them such as 'adenomyosis cases' and 'non-adenomyosis cases'. For the whole study period, the crude incidence rate was 9.9/10 000 person-years in women aged 10 years and over. When considering women aged 25-49 years, who accounted for the majority of all-type cases (68.3%), the crude incidence rate was 18.9/10 000 person-years.³⁵¹ The relative risk (RR) of being hospitalised for endometriosis was 2.97 (95%CI: 2.74–3.21) higher in 47-year-old women than in 25-year-old women. Adenomyosis accounted for the majority of the cases (59%). Based on the French Common Classification of Medical Procedures, the incidence rate was calculated for sub-group of endometriosis: endometrioma: 1.01 person-years, superficial endometriosis

**Country: France**

1.031 person-years, deep endometriosis of the rectovaginal septum: 0.57 person-years, intestinal endometriosis: 0.23 person-years, ureteral endometriosis: 0.012 person-years, vesical endometriosis: 0.028 person-years, and parietal endometriosis: 0.037 (data from 2017).³⁵¹

Between 2011 and 2017, the RR of all-type hospitalised endometriosis increased by 8.5 % (95% CI: 3.9 – 13.4). This increased RR varied by type of endometriosis and age category. During the study period, the RR for 'adenomyosis cases' increased by 15.0% (95%CI: 9.9 – 20.4), while the RR for 'non-adenomyosis cases' increased by 3.6% (95%CI: 0.6 – 6.8). The RR increased by 10.4% (95% CI: 6.2 – 14.8) in women aged 25 years to 49 years, while no increase was observed in younger women.³⁵⁰ The increasing RR over the time may be the result of an increased incidence, but may also be related to with increased use of ultrasound and pelvic MRI, and increased awareness of the disease among patients and clinicians.³⁵⁰

In addition to the influence of time, spatial heterogeneity in incidence was observed. To explain the spatial heterogeneity in incidence, the effect of heterogeneity of healthcare supply has to be tested. Other assumptions can also be explored, such as the impact of environment.³⁵⁰

Organisation of endometriosis care**Overall framework**

In France, endometriosis care is organised into networks whose size is determined by data on the local prevalence of the disease and the number of women of childbearing age.²⁰⁰ The aim is to cover the whole territory to provide close access to care, with particular attention to women in the most vulnerable situations and in areas where there is a shortage of professionals. To this end, the networks can make use of teleconsultation, tele-expertise and day hospitalisation.

Depending on the characteristics of the region, 2 types of network organisation may be envisaged:

- A single coordination system, i.e. a single network providing regional coverage
- An organisation with several regional levels (sub-networks) which are grouped within a regional expert structure to form the overall network. This network coordinates and federates all the sub-networks and carries out the general missions defined by the regional health agency (or delegates this task to the sub-networks by supervising and coordinating them). The sub-networks are responsible for structuring and providing access to a graduated range of health services in their area.²⁰⁰

**Primary health care setting
(level 1)****Definition**

Level 1 includes healthcare professionals from the community or hospital (but not level 2 or 3 and only in case of no professionals are available in the community).²⁰⁰ These professionals have specific skills for diagnosis or overall management or follow-up, including patient information and education, in addition to their detection function.

Skills and professionals

Primary care providers involved in endometriosis care are general practitioners, midwives, gynaecologists, gynaecologists–obstetricians and radiologists.

The doctors are responsive to the diagnosis and the therapeutic care. Their role is to evaluate the intensity of pain, and search for signs suggesting endometriosis and localising symptoms of deep endometriosis.²²⁷ They ask for MRI when needed. The HAS guideline recommends referring to level 2 in case of undetermined ovarian mass or suspicion of deep endometriosis.²²⁷

**Country: France**

The midwives provide care, follow-up, and education in collaboration with a physician or care centre.

Tasks

- These professionals must cover the whole region, providing medical diagnosis and eliminating differential diagnoses, as well as first-line treatment.
- In the context of the implementation of the Personal Health Plan, they perform and coordinate the long-term follow-up (including pain management) of patients cared for at levels 2 and 3. They have access to the MDT to present their patients or just to attend.²⁰⁰

**Secondary health care setting
(level 2)****Definition**

Level 2 includes professionals with expertise in endometriosis from the community or hospital. They are involved in the multidisciplinary investigation and second-line management of patients not responding to initial treatment, particularly for forms of pelvic hypersensitivity. This multidisciplinary approach requires that professionals of level 2 participate in one or more multidisciplinary expertise centres for diagnosis and level 2 management. These multidisciplinary centres are identified by the network and accredited by the regional health agency. The purpose of secondary care is to identify the absence or the presence of deep endometriosis.²²⁷

Skills and professionals

Professionals included in level 2 must have one of the following skills: expert gynaecologists (i.e. with skills in endometriosis), expert sonographers and radiologists (i.e. with experience in the interpretation of pelvic IRM and endovaginally ultrasound)²²⁷, fertility and medically assisted reproduction specialists, and professionals with expertise in the assessment of pain (gynaecologist, algologist, psychologist, sexologist, social worker). These skills are defined regionally by the network and need to be updated. A practitioner may have several of the required skills and full-time practice is not required; mixed practice or practice in several multidisciplinary centres is possible.

Tasks

Level 2 includes care for superficial endometriosis resistant to initial treatment, 'deep superficial' endometriosis (infiltration of the uterosacral ligaments or posterior vaginal fornix) and forms of pelvic hypersensitisation. The following tasks must be performed:

- Performing second-line tests according to the HAS/CNGOF recommendations²²⁷ in other words:
 - Pelvic examination performed by an expert clinician searching for deep endometriosis,
 - Endovaginally ultrasound by expert radiologists or expert gynaecologists,
 - Pelvic MRI interpreted by a expert radiologist,
- Diagnosis and elimination of differential diagnoses,

**Country: France**

- Coordination with the health professionals in the network or sub-network, possibly tele-expertise activity in connection with the level 1,
- Participation in MDT at the institution and between institutions, at the same level and between levels (MDT at level 1 with level 3, in particular, the surgical expert centre for complex endometriosis),
- Multidisciplinary care at level 2:
 - Announcement consultation,
 - Establishment of a personalised health plan and individualised reception project (i.e. based on the information provided by the treating physician, adjustments are made at school for adolescents with endometriosis, such as adjustments to physical activities, administration of pain medication by the school nurse, and adjustments to make up classes missed due to endometriosis.),
 - Medical management of endometriosis resistant to initial treatment and, possibly, surgery for deep endometriosis i.e. infiltration of the uterosacral ligaments or posterior vaginal fornix requiring an operation by a gynaecological surgeon only,
 - Interdisciplinary assessment of pain, in particular in a dedicated day hospital, followed by community care, or if necessary, with a referral to a chronic pain centre recognised by the network or sub-network with a level 3 expertise,
 - Fertility assessment and potential ovarian stimulation of the patient, if needed, in liaison with the assisted medical procreation centres of a level 3,
 - Education and information in collaboration with patient associations,
 - Follow-up, including complications linked to the progression of the disease or due to therapeutic management, and coordination with level 1 for long-term follow-up and implementation of the personalised health plan,
 - Referral to level 3, in particular a surgical referral centre for the management of complex endometriosis.²⁰⁰

**Tertiary health care setting
(level 3)**
Definition

A level 3 centre is a referral surgical centre for complex endometriosis. It is an expert surgical centre that includes clinical, radiological, algological and fertility expertise on-site or by arrangement.²⁰⁰

The network or sub-network may include one or more referral surgical centres. However, there must be at least one level 3 centre per region.

There is no direct access to a level 3 centre. Access is only possible via a referral agreed during an MTD. The patient organisations are mandated to explain to their members how the orientation of a patient with endometriosis is organised.

**Country: France**

Level 3 centres are assessed against quality indicators to ensure access to expertise and quality surgical care. Level 3 centres are labelled by the regional health authority. The licensing standards are defined at the regional level and are based on the type of surgery, the volume of surgery (to define activity thresholds), the skills of the teams and the availability of technical and surgical facilities. The medically assisted reproduction centre and the chronic pain centre must also be labelled by the regional health agency.

Level 3 teams include radiologists specialised in endometriosis, expert medical and surgical gynaecologists, urologists, gastrointestinal surgeons, fertility doctors and algologists. Their skills are recognised and defined by the network. A practitioner may have several of the required skills and full-time practice is not required.

Tasks

The surgical referral centres (level 3 centres) offer their expertise in the management of complex surgical situations such as: deep endometriosis with digestive or urinary tract involvement, extra-pelvic forms, multifocal or recurrent endometriosis, as well as situations requiring expert surgical advice (for example, complications of the disease and sequelae of surgery), etc. The following tasks must be performed:

- Performing third-line tests to identify deep endometriosis including recto sigmoidal and urinary radiological investigations and expert endoscopic investigations,
- Providing expert advices for clinical, radiological, (gynaecological, digestive and urological) surgical, algological and fertility issues for the management of complex situations within level 2 or by means of tele-expertise,
- Coordination of care providers of the network or sub-network,
- Attending the regional MDT,
- Cross-sectional and specialised care for complex endometriosis:
 - Announcement consultation,
 - Establishment of a personalised health plan and individualised reception project,
 - Medical management of complex situations, including diagnosis, assessment (functional exploration, endoscopy, etc.) and specific treatment of the pelvi-perineological, urological and digestive functional consequences of endometriosis (linked to the course of the disease or sequelae secondary to therapeutic management) and even, where appropriate, access to interventional radiology.
 - Surgical management of deep urological, digestive and extra-pelvic forms, involving a surgical team with expertise in visceral, urological and gynaecological surgery.
- Algological expertise following interdisciplinary pain assessment, particularly day hospitals in level 2, and pain management by agreement with a chronic pain centre,



Country: France

- (In)fertility expertise, followed by infertility management under agreement with a medically assisted reproduction centre;
- Education and information in collaboration with patient associations,
- Follow-up, including post-operative follow-up and coordination with level 1 for long-term follow-up and implementation of the personalised health plan.²⁰⁰

Initiatives to install/enhance multidisciplinary care The network and sub-network organisation enables a multidisciplinary approach including medical and surgical management of the disease, fertility issues and chronic pain management.²⁰⁰ However, networks have not yet been set up throughout France as legal framework was published in 2022.

Access to care All patients with endometriosis have direct access to primary and secondary care. Yet, access to tertiary care is restricted to patients with deep endometriosis.^{352, 353}

Any other valuable information Launched in 2018, a cohort of French-speaking adults with chronic diseases are followed-up through online questionnaires to collect patient-reported outcome measurements (PROMs) and patient-reported experience measurements (PREMs). A random sample of 1 000 participants from the 9 000 patients with endometriosis included in the cohort was used to describe the patients' perspective on how to improve endometriosis care.¹³⁴ Among the 10 areas of improvement most frequently elicited by patients, three related to access to care:

- Reimburse medicines and care not currently reimbursed, and transport related to care;
 - Provide help in accessing a doctor with expertise in the disease and with human qualities;
- Reduce waiting times for appointments and medical exams.

Reference centres for endometriosis

General info Each region must have at least a network including at least level 1 and level 3 centres.

Who is referred to reference centres? As foreseen the national plan for endometriosis¹²² the less complex endometrioses in need of surgical management can be managed in level 2 centres but the more complex endometrioses are managed in level 3 centres (see above).
As argued by some authors³⁵⁴, the access of level 3 is limited to endometriosis classified as complex or severe.

Licensing standards Each region must organise the endometriosis care network including primary and specialised care. Centres of reference must meet the specifications of the region in which they are located.¹²²
The core criteria for the organisation of the network and the division of tasks between levels are defined by the Ministry of Health.²⁰⁰ However, the implementation of the networks can vary from one region to another, leading to some differences in the licensing standards. For example, in the Nouvelle-Aquitaine region, a level 3 centre must have at least of one surgeon who has performed at least 20 surgical procedures per year for the treatment of complex endometriosis over the last 2 years. This surgeon must also have participated in research activities and the collection date for the regional cohort.³⁵⁵ In contrast, the Grand Est region did not refer to activity threshold.³⁵⁶

**Country: France****Quality assurance**

So far, the quality of care in the various reference centres has not been evaluated. However, the following quality indicators have been proposed in the literature:

- Quality indicators for the MDT³⁵²
 - Presence of a standardised patient presentation form prior to an MDT with mention of the quorum (practitioners present at the MDT)
 - Conclusions of the MDT with reporting of the therapeutic options and additional work-up.
 - Quality indicators for the clinical assessment³⁵²
 - Assessment of endometriosis-related pain (dysmenorrhoea, deep dyspareunia, painful defecation and urination, and chronic pelvic pain)
 - Vaginal palpation
 - Speculum examination
 - Quality of life assessment including short-form endometriosis health profile questionnaire (EHP-5)³⁵⁷ or the rate of absenteeism from school or work
 - Quality indicators for imaging assessment³⁵²
 - Double reading of pelvic MRI performed
 - For complex endometriosis, 3rd line entero-MRI and diaphragmatic MRI in 0.06% of cases
 - Quality indicators for surgical care based on the FRIENDS cohort³⁵⁸
 - 20 surgeries for colorectal endometriosis per year and per centre³⁵⁴
 - 8 colorectal surgeries per operator and per year³⁵⁴
- 40 procedures per year and per hospital for colorectal endometriosis with rectovaginal fistulae^{187, 354}

Dedicated funding of reference centres

In addition to the funding for care and research, the networks are also funded by the regional health agencies for operating costs, medical and administrative coordination time required to set up and coordinate the graded care offering, organise MDT, and monitor activities for the regional health agency.²⁰⁰

The total budget for all region is estimated at €4.5 million.³⁵⁶

Legal framework

INSTRUCTION N° DGOS/R4/2022/183 of 12 July 2022 provides for the definition of networks, their organisation, legal form, governance, funding, ethical principles, missions and the structuring of care within networks (i.e the different levels see above).²⁰⁰



Country: France

Is there a liaison between reference centres and the primary and secondary level?

Coordination between care providers of a network is a mission of level 3 (see above tasks described above). In addition, as level 3 is only accessible by referral, the care providers may attend the MDT organised by level 3.²⁰⁰

During the MDT, a standardised form is completed for each patient, indicating the context of the MDT (date, reason for the MDT), the clinical situation (history of endometriosis, relapses, location of deep pelvic endometriosis lesions), the results of the work-up (imaging, biology, etc.) and the treatment proposal made at the MDT³⁵⁴ and eventually the addition work-up.³⁵² The names of the doctors attending the MDT and the name of the patient's referring doctor are recorded. This standardised form is used to make the liaison between reference centres and the referring doctor.

Public reporting/Published evaluation of the reference centres?

No data available

Any other valuable information

Recognition of endometriosis as a chronic condition

Is endometriosis recognised as a chronic condition?

Yes since 2022. The status is not automatic. Endometriosis can be considered as an ALD 31 i.e. a serious condition with a foreseeable course of more than 6 months and the treatment of which is particularly expensive.²¹⁹

Licensing standards²¹⁹

- The treatment of endometriosis must necessarily include medication.
- 2 of the following 4 criteria are also compulsory and must therefore be present:
 - A forthcoming hospitalisation
 - Repeated technical medical procedures
 - Repeated biological procedures
 - Frequent and regular paramedical care

How is the recognition installed?

The treating doctor must submit a request to the health insurance, together with a care protocol. The health insurance decides whether to grant 'ALD 31 status' on a case-by-case basis.

Consequences for patients

ALD 31 status means that co-payments are waived for procedures covered by health insurance at the agreed rates. The following are not covered: supplements (i.e., extra fees), alternative medicine and fixed charges.

Consequences for the health care setting

No info

Funding

No info

Evaluation of endometriosis being recognised as a chronic condition

No info

Any other valuable information



Country: France	
Endometriosis registry	
Is there an endometriosis registry?	Not yet, but it is one of the missions of the reference centres to collect data in the future. The data collection is organised at the regional level by the regional health agencies. ²⁰⁰
Who is in charge?	Level 3 centres
Legal framework	INSTRUCTION N° DGOS/R4/2022/183 of 12 July 2022
Funding	Regional Health Agency
Criteria	Not yet implemented
Coverage	Not yet implemented
Data collected?	Too early
Results	Too early
Any other valuable information	
Guidelines and quality indicators	
Guidelines	The HAS published the national guideline for endometriosis care in December 2017.²²⁷ It covers recommendations for primary and specialised care. There is no legal obligation to follow the guideline related to endometriosis care. However, the national plan for endometriosis foresees that reference centres must respect the recommendations of the HAS.¹²²
Quality indicators	There are no recommended quality indicators reported in the HAS guideline. ²²⁷
Care pathway for endometriosis	The HAS proposed a care pathway as follows: first-line investigations performed by GPs, midwives or gynaecologists ²²⁷ , second-line investigations and endometriosis work-up performed by an expert clinician and an expert physician sonographer ³⁵⁹ and third-line diagnostic investigations requested by specialists in case of suspected endometrioma, rectosigmoid endometriosis or urinary tract endometriosis).
Any other valuable information	
National action plan on endometriosis	
National action plan on endometriosis	The national plan for endometriosis plan covers the period 2022-2025. The plan involves not only the Ministry of Health, but also the Ministry of Gender Equality, Diversity and Equal Opportunities, the Ministry of Education, Youth and Sport and the Ministry of Labour, Employment and Social Inclusion. The national plan is dedicated to health professionals (including scholar nurses) but also to patients' relatives, patients' workplaces, the education sector, and the sports sector. The national plan pays attention to specific situations such as economic vulnerability and disability.
Key actions	The plan is divided into 5 domains, with 18 objectives translated into 50 measures and 153 actions.

**Country: France****Domain 1: Inform, communicate and raise awareness**

Objectives:

- Set up an institutional communication system
- Communicate with the general public
- Communicate with patients and their families / relatives

Domain 2: Strengthen training for professionals

Objectives :

- Initial training for healthcare professionals
- Lifelong training for healthcare professionals
- Raise awareness of endometriosis among other professionals in contact with the disease (teachers, youth movement leaders, educators, social workers, school nurses, occupational physicians, sports physicians).

Domain 3: Better detection of the disease

Objectives:

- Improve primary and secondary prevention
- Improve the reliability of reference diagnostic imaging tests
- Improve knowledge of the natural history of the disease to improve diagnosis

Domain 4: Guarantee comprehensive, personalised care throughout the country

Objectives:

- Organise the care pathway
- Guarantee territorial equity and access to care
- Management of chronic pain

Domain 5: Promote research and innovation

Objectives:

- Structure and develop dynamic research into endometriosis in France
-



Country: France

- Develop epidemiological knowledge of endometriosis
- Promote innovation in endometriosis care

Additional objectives:

- Make endometriosis an issue of equality
- Provide information, prevention and support in schools and sport clubs
- Provide training on the impact on working life and adapt working conditions

Evaluation	No info
Funding	No info
Any other valuable information	No info

Training about endometriosis

Training on endometriosis during the professional curriculum of primary care professionals

The national endometriosis plan provides a revision of the legal framework governing nurses' qualifications to allow them to administer certain medicines without a prescription in cases of low-intensity pain.¹²²

A study conducted in 2021-2022 in the south of France (Provence-Alpes-Côte d'Azur) shows that in a group of 133 GPs performing gynaecologic visits, 61.7% achieved a correct response rate of over 75% when testing knowledge regarding the diagnosis and management of endometriosis. The authors of the study concluded that there is room for improvement.³⁶⁰

Training on endometriosis during the continuing medical education of primary care professionals

In 2013, a study showed that additional training in gynaecology was associated with better endometriosis care provided by GPs.³⁶⁰

Other initiatives to improve the knowledge on endometriosis among primary care professionals

See National plan

HAS (Haute Autorité de Santé) published specific material for the GP. This is a 10-page document that includes a description of symptoms and care pathways, as well as recommendations for clinical assessment, quality of life assessment, communication with patients and treatment.

Training on endometriosis during the professional curriculum of medical specialists involved in endometriosis care

Pellerin et al.³⁶¹ stated that residency training does not allow gynaecologists to perform complex pelvic procedures in patients with endometriosis.

The training of medical specialists in endometriosis is a mission of the reference centres (see above)

Training on endometriosis during the continuing medical education of medical specialists (involved in endometriosis care)

Pellerin et al.³⁶¹ report that gynaecologists need specific additional training and practical experience to perform safe surgery for bowel or urinary endometriosis. They add that colorectal and urological surgeons remain the main players.



Country: France

Other initiatives to improve the knowledge on endometriosis among medical specialists See National plan

Any other valuable information

Awareness about menstrual health and endometriosis

Education on menstrual health Sex education takes place in primary schools. The timing is chosen by the school. In addition, at least three sex education sessions are yearly organised in secondary schools (i.e. 'collèges' for pupils aged 11 to 15 and 'lycées' for pupils aged 15 to 18). These sessions are organised by a team of trained volunteers from the school or by external partners with national or academic accreditation. Three areas of knowledge and skills need to be covered: biology, psycho-affective and social aspects. Anatomy, physiology and puberty are covered when biology is taught. ³⁶²

Education on endometriosis The national plan to combat endometriosis provides for the Ministry of Education, Youth and Sport to provide information and raise awareness in schools and sports. In particular, endometriosis and dysmenorrhoea will be included in sex education (i.e. in the annual sessions in secondary schools. Coaches, sports teachers and sports federations will be informed, e.g. through national information campaigns. Educational teams will be made aware of how to support and guide students with endometriosis. ¹²²

Awareness campaigns on endometriosis (laymen) The SCGP (Société de Chirurgie Gynécologique et Pelvienne) supported the development of a tool to support women with a suspicion of endometriosis to find their way in the care pathway. This tool combines a questionnaire and a saliva test based on the analysis of micro-ribonucleic acid (miRNA) to detect endometriosis. The reimbursement of the test by the health insurance is currently under review. It gives the patient a risk probability and proposes a care pathway. The results are formatted so that they can be transmitted to healthcare professionals. Preliminary data on the validation of the tool was published in June 2023. ⁶⁰

The College of midwifery proposes posters to inform the midwives' patients about endometriosis. ^{363, 364}

Associations are very active in France since the years 2000' and are supported by famous actresses such as Julie Gayet, former President François Hollande's partner. EndoFrance, ENDomind, Info-endometriose, Femmes Endo &Co, EndoAction, Info-endometriose, Endoblum are some examples of patient associations.

Awareness campaigns on endometriosis (health professionals) HAS had developed a video on recommendations for endometriosis care for healthcare professionals. ³⁶⁵

Any other valuable information

Any remaining thoughts, suggestions, comments, ...

Endoconnect, an App developed by Ziwig® (a biotech firm), supports patients in evaluating the probability of endometriosis risk and allows them to summarise medical data for healthcare professionals. ³⁶⁶

EndoFrance refers to 7 apps on its websites. ³⁶⁷

Of these, 3 are generic apps designed to inform patients or help them manage their pain. The other 4 are specifically dedicated to endometriosis patients: Follow Metrios, LUNA, shinyDEVA and NO ENDO.

**Country: France**

Follow Metrios is a tool that helps patients record information about their symptoms, treatments and medical consultations.

LUNA and shinyDEVA are two apps that offer a self-administered questionnaire to calculate the patient's likelihood of having endometriosis. The shinyDEVA questionnaire has a specificity of 98.0% and a positive likelihood ratio of 30.5 to identify high-risk patients.³⁶⁸

No Endo (National Endometriosis Observatory) is an app that allows patients in a hospital (CHU Clermont-Ferrand) to record their medical and surgical history, quality of life, and the impact of symptoms on urinary, digestive and sexual function. These data are sent to the doctor before the consultation and are used to build up the medical file, to provide feedback to the treating doctor and to be included in a database for research purposes.



Appendix 5.7. Organisation of endometriosis care in Germany

The content provided in Table 44 was reviewed by Professor Karl-Werner Schweppe, who is executive board member of the Stiftung Endometriose-Forschung in Germany.

Table 44 –rganisation of endometriosis care in Germany

Country: Germany	
General information	
The health care system	Germany has a multi-payer health system based on health insurance, providing near universal health coverage.³⁶⁹ Health insurance is compulsory; people can be insured by the social health insurance or opt out of social health insurance coverage and enrol in private health insurance. Overall, 11% of the residents is covered by private health insurance; 89% by SHI. The system currently consists of 103 sickness funds and 41 private health insurance companies.³⁶⁹ Statutory health insurers, who provide the health insurance, have contracts with many institutions and organizations, such as physician associations and hospitals.³⁷⁰ Everyone covered by statutory insurance has equal right to medical care; premiums are based on income (up to a certain level of income; above that, members pay the same maximum premium). As a federal republic, the Federal Ministry of Health in Germany defines only the legal framework for the health system, while regulatory details are specified in directives issued by the Federal Joint Committee.³⁶⁹ This committee consists of representatives of the sickness funds, physicians, dentists and hospitals, and three independent members. It is the highest federal decision-making body in the healthcare system and makes decisions regarding insurance coverage of medical services. Moreover, the Federal Joint Committee assures healthcare quality. The states are responsible for supervision at the regional level and for medical training public health and hospital planning and investments.³⁶⁹ All physicians whose services are covered by statutory insurers belong to associations of statutory insurance physicians; for dentists and other healthcare providers, similar associations have been installed.³⁷⁰ Moreover, at the individual federal state level, all physicians, psychotherapists, pharmacists and dentists belong to their respective state chamber. A chamber is responsible for supervision of the profession, professional certification and medical board examinations. Primary care consists of self-employed “family doctors”, most of which have “<i>Kassenzulassung</i>” (statutory health insurance accreditation), which means their services are reimbursed by health insurance. In Germany, general practitioners, internists and pediatricians can all be considered as “family doctors” and thus primary care. These doctors can refer you further for specialist problems, but referral is not necessary and patients can freely seek services from specialists. There are both individual practices, joint practices and medical care centres, with multiple professionals working together. Some of the larger practices offer diagnostic techniques or day surgery (<i>Praxiskliniken</i>). Hospitals can be funded by public funds (state or municipality), or they can be charity-run or church-run. Privately-run hospitals also exist, some of which will only treat privately-insured patients.



Country: Germany

In the publicly funded hospitals, usually accommodation and meals are not covered by insurance and are part of a separate “contract” between patient and hospital.³⁷⁰

Period of data collection

August - December 2023

Endometriosis in Germany

Prevalence of endometriosis

According to a 2022 retrospective cross-sectional study, based on data from IQVIA Disease Analyzer database (covering 3% of all outpatient practices in Germany), the prevalence of endometriosis in Germany increased from 0.53% of girls & women aged 14 and older in 2010 to 0.66% in 2019.³⁷¹ The denominator was the number of women with at least one visit to one of 136 gynaecological practices in Germany; the numerator was a documented diagnosis of endometriosis,³⁷¹ as a result, a certain level of underestimation cannot be excluded.

Another study from 2012, based on a statutory health insurance-based cohort in Germany, found a prevalence of diagnosed endometriosis of 8.1 per 1000 women (aged 15-54). Highest prevalence occurred in women 35-44 years of age (12.8 per 1000).³⁷²

Organisation of endometriosis care

Primary health care setting

No specific initiatives at the primary health care level were found.

There is no gatekeeping role for general practitioners in Germany, therefore patients can choose to go directly to certified endometriosis practices or clinics.³⁷⁰

Secondary health care setting

Certified Endometriosis Centers: since 2005, certification for specialized endometriosis centers has been implemented in Germany. It is a multistep concept (three levels with increasing specialization and advanced care) with different requirements for certification according to the level (cf. infra).¹⁵⁹

The two first levels of certified centers, ‘Endometriosepraxis’ and ‘Endometrioseklinik’, can be regarded as secondary health care structures.

Tertiary health care setting

The third level of certified Endometriosis centers (‘Endometriosezentrum’) can be regarded as a tertiary health care structure.¹⁵⁹ Cf. infra for more details.

The link between secondary and tertiary health care is established in the requirements for certification of the different levels of Endometriosis centers.¹⁵⁹

Care pathway for endometriosis

No care pathway for endometriosis could be found.

Initiatives to install/enhance multidisciplinary care

Interdisciplinary care is a core aspect of the structure of certification of specialized Endometriosis centres and participation to interdisciplinary initiatives (such as interdisciplinary case discussions) is a requirement for certification.¹⁹⁹

Proximity of care

Access to care

Access to secondary healthcare in Germany is generally good as there is no gatekeeping role for general practitioners.³⁷⁰

**Country: Germany**

However, access to high-quality endometriosis care may be suboptimal. The QS ENDO Real study, a survey in gynaecology centres in German-speaking countries in Europe (86.8% in Germany) in 2016, showed that around 60% of patients with endometriosis were not treated in certified hospitals; 87.2% of the centres that responded to the survey were not certified.³⁷³

Moreover, a survey from 2012 in 171 women with endometriosis from Germany and Austria found that there was a 10.5-year delay between symptoms (pelvic pain) and diagnosis.⁶¹ In addition, the same survey found that 74.3% of women had been misdiagnosed initially, which was associated with a longer time to diagnosis.⁶¹

Any other valuable information**Reference centres for endometriosis****General info**

Certification of medical institutions for specialized endometriosis care has been implemented since 2005.¹⁵⁹ There are 90 certified medical institutions in Germany for endometriosis care.³⁷⁴ EuroEndoCert does the certification of these institutions on behalf of the Endometriosis Research Foundation (SEF) and the European Endometriosis League (EEL).¹⁹⁹

There are three levels of care:¹⁵⁹

- Level I: 'Endometriosepraxis' (endometriosis practice): subspecialized gynaecological (private) practice
- Level II: 'Endometrioseklinik' (endometriosis clinic): in addition to the care provided in the endometriosis practice, they also provide surgical treatment (usually hospital-based)
- Level III: 'Endometriosezentrum' (endometriosis centres): comprehensive endometriosis care, including highly specialized endometriosis surgery for deep endometriosis (plus interdisciplinary visceral and urological operations); offering special training courses for medical and surgical treatment of endometriosis. In addition, these centers must participate in scientific studies.

Level II & III must report patient treatment data annually to the SEF and organize scientific symposia.¹⁵⁹

Who is referred to reference centres?

Referral is done at the initiative of the treating gynaecologist (e.g. if there is an indication for surgery according to the gynaecologist) or the patient herself.

There are no rules for reimbursement of treatment at specific levels; if a treatment is carried out at a centre without certification, they will still get reimbursed by the health insurance companies. (*Karl-Werner Schweppe, personal communication*)

Licensing standards

The following licensing standards have been stipulated by the Endometriosis Research Foundation:¹⁹⁹

- 'Endometriosepraxis' (endometriosis practice)
 - o Guideline-compliant diagnosis, therapy and patient counseling
 - o Participation in interdisciplinary endometriosis conferences
 - o Collaboration with an Endometriosezentrum (level III), a fertility center, a psychological counseling practice, pain clinic and physiotherapy
 - o Collaboration with the patient association 'Endometriose-Vereinigung Deutschland' and/or with self-help groups

**Country: Germany**

- Led by a gynaecology specialist who has followed Endo I and Endo II training or has a certificate of SEF (Stiftung Endometrioseforschung)
- The head of the practice has to attend at least one endometriosis training per year
- Recommended to also attend conferences on endometriosis; alternatively, the specialist should follow at least a one-day internship in a certified Endometriosezentrum
- At least 50 treated patients per year
- Documentation requirements:
 - Use of a questionnaire for patient history and symptoms
 - Yearly registration of a minimal dataset (basisdokumentation)
- 'Endometrioseklinik' (endometriosis clinic)
 - Guideline-compliant diagnosis, therapy and patient counseling
 - Implementation of surgical treatment
 - Interdisciplinary surgical case discussions (with at least radiology and abdominal surgery)
 - Collaboration with an Endometriosezentrum, a fertility center, a psychological counseling practice, pain clinic and physiotherapy
 - Collaboration with the Endometriose-Vereinigung Deutschland and/or with self-help groups
 - Head of the clinic must be a specialist in Gynaecology and a surgeon dedicated to endometriosis
 - Head of the clinic must have a qualification certificate for endometriosis care by obtaining:
 - Endometriosis certificate (basis course, advanced course) by the Arbeitsgemeinschaft Endometriose (AGEM) or SEF qualification course
 - Masterclass endometriosis as offered by the AGEM
 - These requirements are needed for all endometriosis surgeons working in the clinic in the case of recertification after 3 years. (*Karl-Werner Schweppe, personal communication*)
 - Certificate of further education for all endometriosis surgeons working in the clinic:
 - At least one endometriosis advanced training per year
 - Recommended to also attend conferences on endometriosis; alternatively, the specialist should follow at least a one-day observership in a certified Endometriosezentrum
 - Activities:
 - Proof of at least 100 treated patients per year
 - Of which at least 50 surgical patients^{hhhh}

^{hhhh} Surgical patients are defined as: age < 50 years; each patients can only be assigned to one surgeon; dedicated surgeons must carry out or assist in at least 30 surgeries per year; at least 80% of elective surgeries are carried out by dedicated surgeons; histology must be available for all cases; hysterectomies also count if the indication is dysmenorrhea and adenomyosis as proven by histology; for laparoscopic surgery, a false-negative rate up to 20% is accepted for histology.

**Country: Germany**

- The head of the center has to perform or assist in at least 30 surgeries per year
 - Or, if the total number of surgical cases in the clinic is just above the minimum (50-70), the head of the center must have performed or assisted in at least 50 surgeries per year
 - Evidence of at least one further training course (including in-house training) on the subject of endometriosis for all doctors and medical staff within the last 3 years
- Documentation requirements:
 - Documented structured patient history, e.g. by applying the questionnaire of the endometriosis guidelines by Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF)
 - Submission of a structured annual report (template can be found on the EuroEndoCert website).
 - Standard operating procedure on conservative treatment should be prepared, taking into account local particularities (e.g. agreements with health insurance companies) (*Karl-Werner Schweppe, personal communication*)
- 'Endometriosiszentrum' (endometriosis centre) - in addition to the criteria defined for the endometriosis clinics, endometriosis centres also have to fulfill the following criteria:
 - Performance of complex and interdisciplinary surgery
 - Organization of monthly interdisciplinary endometriosis conferences, which are also accessible to external and cooperating partners (such as the clinics) OR documented interdisciplinary therapy plans
 - Supra-regional hospital network for specialized services
 - Scientific activity:
 - In the last 3 years, publication of at least 1 paper on primary research, listed in Web of Science, with first or senior author from the centre
 - or participation in a clinical trial (multicentre study with ethical clearance) with inclusion of at least one patient
 - or participation in ongoing third-party funded project
 - in addition, at least 1 assignment per year as speaker at a conference (abstract, lecture, poster)
 - or the publication of a review paper
 - or publication of case report
 - or publication of a book chapter
 - The head of the centre or a designated surgeon must have an additional qualification in the field of endometriosis (e.g. qualification course of AGEM)
 - The head of the centre must have demonstrable expertise in the field of minimally invasive surgery
 - OR have the specialty title of gynaecological oncology or gynaecological endocrinology (or equivalent title from other countries)
 - The same requirements are also highly recommended for the other gynaecologists working in the centre

**Country: Germany**

- Activities (per year):
 - At least 100 surgical patients^{hhh}, of which at least 10 cases with organ-transcending infiltrating spread (bladder, intestine, ureter)
 - At least 10 documented interdisciplinary therapy plans
 - Realization of at least one further training course on the topic of endometriosis for doctors and medical staff per year
- Documentation requirements:
 - Documented structured patient history, e.g. by applying the questionnaire of the endometriosis guidelines by AWMF
 - Submission of a structured annual report (template can be found on the EuroEndoCert website)
 - Data entry form for scientific questions
 - Standard operating procedure on conservative treatment should be prepared, taking into account local particularities; in particular on how to deal with patients who have undergone previous surgical treatment for endometriosis

As core interdisciplinary members of an endometriosis centre, the following specialisms were identified: gynaecology, visceral surgery, urology, radiology and pathology, as well as patient interest groups, nutritional counselling, physiotherapy, pain therapy, assisted reproductive technologies and rehabilitation.¹⁵⁹

Quality assurance

EuroEndoCert carries out all certification and re-certification since 2016.¹⁹⁹

This organization is a physician-led service provider and provides certification for endometriosis clinics on behalf of the SEF and EEL.²⁰⁹

The certification lasts for 3 years, after which the status is re-evaluated by EuroEndoCert. Recertification does not occur automatically.¹⁵⁹

Despite the extensive requirements for certification and its quality assurance, a recent survey in 44 of these certified centres indicated that a lot of required indicators were not entirely met, such as samples taken for histological examination (taken in 84.1%), guideline-compliant classification system use (46.1% of patients).³⁷⁵

Dedicated funding of reference centres

There is no dedicated funding of the certified centres. A consultation or operation for endometriosis is reimbursed at the same rate regardless of the level of care; this is one of the reasons why some practices or clinics are not interested in certification, as they would have to treat more complicated cases without better remuneration. (*Karl-Werner Schweppe, personal communication*)

A position paper on better care for endometriosis, which also included recommendations for alternative funding of endometriosis centres, was published by AGEM and the Arbeitsgemeinschaft Gynäkologische Endoskopie (AGE) in 2023.³⁷⁶ This paper was also supported by the Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (DGOG).



Country: Germany

In this paper, they recommend endometriosis treatment in certified clinics, especially for surgery, and suggest to adapt reimbursement to be better adapted to the complexity of endometriosis treatment. Further, they recommend cross-sectoral and interdisciplinary treatment of endometriosis pain, earlier recognition of endometriosis by adapting reimbursement to also cover pain history and assessment, and further extending endometriosis trainings to other specialties such as anaesthesiology. Finally, they also advocate for better funding for research in the field of endometriosis.³⁷⁶

Legal framework

There is no legal framework; certification as endometriosis centre is not currently recognized by healthcare funding institutions. (*Karl-Werner Schweppe, personal communication*)¹⁵⁹

Is there a liaison between reference centres and the primary and secondary level?

Patients are referred to the centres by doctors in private practices (first line).¹⁵⁹

Level I centres must collaborate with level II and III centres; they are ideally considered as “satellite” centres of the respective level II or III centres. A level II centre is required to collaborate with a level III centre if they do not perform interdisciplinary surgery themselves. Therefore, liaisons between the different levels of care are entrenched in the design of the certification structure.¹⁵⁹

Public reporting/Published evaluation of the reference centres?

Any other valuable information

Recognition of endometriosis as a chronic condition

Is endometriosis recognised as a chronic condition?

Endometriosis is not recognized as a chronic condition in Germany, despite advocacy by the SEF and the patient support groups. (*Karl-Werner Schweppe, personal communication*)

Licensing standards

NA

How is the recognition installed?

NA

Consequences for patients

NA

Consequences for the health care setting

NA

Funding

NA

Evaluation of endometriosis being recognised as a chronic condition

NA

Any other valuable information

NA

Endometriosis registry

Is there an endometriosis registry?

There is no official German register for endometriosis.

**Country: Germany**

As part of accreditation, clinics and centres are also required to deliver an annual report with a “minimal dataset” of information on inpatient vs outpatient treatment, surgeries vs conservative therapy and post-surgical follow-up for their respective centre.³⁷⁷ The template of these annual reports can be found on the EuroEndoCert and SEF website.²⁰⁹ The information from these reports is compiled by SEF into an annual report.³⁷⁷

The annual reports compiled by the SEF are not made publicly available, but feedback is given to the endometriosis clinics and centres by sending them an overview of where their numbers (e.g. number of surgeries) are located compared to other centres at the same level of care. (*Karl-Werner Schweppe, personal communication*)

An online documentation system for structured reporting of endometriosis patient characteristics was introduced in 2013 in 5 hospitals and surgical outpatient centres.³⁷⁷ This system is the basis for the International Endometriosis Evaluation Program (IEEP) study, which was rolled out in different German endometriosis centres since 2014.³⁷⁸ However, only a small number of university centres are participating in this study. (*Karl-Werner Schweppe, personal communication*)

Who is in charge?	Not found
Legal framework	The certified centres are required to submit an annual report with the minimum dataset to stay certified; however, there is no legal framework of certification. (<i>Karl-Werner Schweppe, personal communication</i>)
Funding	Not found
Criteria	Restricted to those treated in certified centres
Coverage	Restricted to those treated in certified centres (not only surgical patients)
Data collected	For the annual report of the SEF, a minimal dataset is collected. Templates of the collected data can be found on the SEF website and the EuroEndoCert website. (<i>Karl-Werner Schweppe, personal communication</i>) Examples of the variables collected: how many patients were seen in an ambulatory setting, how many were hospitalized, how many operations were performed, what were the indications for surgery (e.g. pain, infertility, ...), how many diagnoses of endometriosis were made, ... Note: all of these data are aggregated per centre; there is no collection of data on a patient level. For the IEEP, the electronic case report form (eCRF) collects data on 23 variables at registration; 41 variables for the medical history and 22 endometriosis-specific variables. For surgical patients, another 18 variables are recorded. Post-surgery follow-up is recorded by another 10 variables.³⁷⁷ Example of the variables collected: age at registration, age at first diagnosis, age at menarche, menstrual cycle length, duration of menstrual bleeding, number of pregnancies/live births/abortions, oral contraceptive intake, body mass index, ...³⁷⁷
Results	Burghaus et al. published an analysis, comparing patients treated surgically in their certified centre in Erlangen to patients in whom endometriosis was diagnosed as an incidental finding during surgery, who were referred from other outpatient clinics. This study used the data available in the IEEP database. No outcome comparison was done in these two cohorts. Of note, both cohorts were treated surgically in the same centre; the only difference is that the second cohort was referred without a suspicion of endometriosis from other outpatient clinics. ³⁷⁸


Country: Germany

No data with regards to outcome of treatment in certified centres exists at the moment. (*Karl-Werner Schweppe, personal communication*)

Any other valuable information
Guidelines and quality indicators

Guidelines The guideline "Diagnostik und Therapie der Endometriose" was first developed in 2006; its latest edition dates from August 2020 (published in 2021).³⁷⁹ The guideline has been developed and updated by the DGOG, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe (OEGGG) and the Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe (SGGG). It offers guidance on diagnosis, classification, conservative management and surgical treatment. It also discusses special situations in endometriosis, such as the desire to have children or endometriosis and carcinoma.³⁷⁹

Quality indicators The development of quality indicators according to AWMF-defined criteria is planned.³⁷⁹ The guidelines are currently being updated and there is a working group in the Guidelines Commission to define evidence-based quality indicators. The publication date for the updated guidelines is 2024. (*Karl-Werner Schweppe, personal communication*)

Care pathway for endometriosis Not found

Any other valuable information The QS Endo Real study found that of 1014 gynaecological departments in the German-speaking parts of Europe (of which 86.8% in Germany), only 44.4% to 66.4% used the guideline-recommended classification system for endometriosis, and only 27% of hospitals used the guideline-recommended classification system for deep endometriosis.³⁷³ Guideline compliance with regard to diagnosis and treatment is among the criteria for accreditation of the specialized centres. However, a similar survey in certified centres (QS Endo Pilot study) found that even within these certified centres, guideline-recommended classification for endometriosis was used in only 46.1% of patients (cfr supra).³⁷⁵

National action plan on endometriosis

National action plan on endometriosis There is no national action plan at the moment, however the Endometriosis Association Germany issued a petition called "#EndEndoSilence", which was addressed to the Minister of Public Health in the beginning of 2022, with the request to pursue a national strategy for endometriosis.³⁸⁰ In particular, increased funding for research into the disease and the launching of national awareness and information campaign on the disease were suggested.³⁸⁰

Key actions NA

Evaluation NA

Funding NA

Any other valuable information
Training about endometriosis

Training on endometriosis during the professional curriculum of primary care professionals Not assessed


Country: Germany

Training on endometriosis during the continuing medical education of primary care professionals

Not found

Other initiatives to improve the knowledge on endometriosis among primary care professionals

Not found

Training on endometriosis during the professional curriculum of medical specialists involved in endometriosis care

Not assessed

Training on endometriosis during the continuing medical education of medical specialists (involved in endometriosis care)

The EEL organizes a masterclass endometriosis.²²³

The SEF has been organizing seminars for qualification of gynaecologists as endometriosis experts since 2013; since 2022, these qualification courses have been offered by AGEM in the DGGG.²²⁹

These courses are also mentioned among the criteria for certification (cf. supra).

Other initiatives to improve the knowledge on endometriosis among medical specialists

Any other valuable information
Awareness about menstrual health and endometriosis

Education on menstrual health

Not assessed

Education on endometriosis

Not assessed

Awareness campaigns on endometriosis (laymen)

Not assessed

Awareness campaigns on endometriosis (health professionals)

Not assessed

Any other valuable information

Any remaining thoughts, suggestions, comments, ...



Appendix 5.8. Organisation of endometriosis care in the Netherlands

The content provided in Table 45 was reviewed and validated by Prof. Dr. Annemiek Nap, Head of department Obstetrics & gynaecology, Professor at RadboudUMC.

Table 45 – Organisation of endometriosis care in the Netherlands

the Netherlands	
General information	
The health care system	The Netherlands healthcare system is organised following a gatekeeper system. The high numbers of outpatient contacts in contrast with low rates of hospital discharges, prove a strong primary care and outpatient specialist treatment to keep people out of hospitals.³⁸¹ Financially the health care system is organised following three coverage schemes to provide broad health coverage. A competitive social health insurance system for curative care, mandates all residents to purchase insurance policies that cover a defined benefits package set by the government (covers specialist care, primary care, pharmaceuticals, medical devices and mental health care). A second system is the single-payer system for long-term care, carried out by the regionally dominant health insurer. The third system is a tax-funded social care scheme implemented by the municipalities (screening, vaccination and health promotion).³⁸¹
Period of data collection	July - November 2023
Endometriosis in the Netherlands	
Prevalence of endometriosis	Currently no country-specific prevalence numbers are reported in literature. The prevalence of endometriosis in the Netherlands is similar to other European countries and country-specific numbers may be expected by the end of 2023. <i>(Personal communication with reviewer)</i>
Organisation of endometriosis care	
Primary health care setting	The general practitioner (GP) is responsible to identify patients in an early disease stage. Whereafter the GP refers patients with (a suspicion of) endometriosis to hospital/specialist care (e.g. gynaecologist).³⁸¹ A GP can start hormonal treatment without a (definitive) diagnosis or specialist opinion (pragmatic approach and in some cases a low sense of urgency about confirming the diagnosis).³⁸² A questionnaire study on the knowledge of endometriosis and available treatment strategies among general practitioners (n=101) showed that GPs annually encounter 2.8 women with a suspicion of having endometriosis and 56.7% primarily refers patients to a gynaecologist for consultation or diagnostic tests.³⁸³
Secondary health care setting	In most cases patients will be referred to specialist care (e.g. gynaecologist) by their GP. This is necessary to receive reimbursement for the provided care by their health insurers.



the Netherlands

In 2016, the Dutch gynaecologists' opinion regarding the organisation of endometriosis care was evaluated by a nationwide survey study.³⁸⁴ This survey was conducted among all hospitals in the Netherlands and for each hospital one gynaecologist was asked to respond (n=67) to the survey. The following results were obtained from this nation-wide survey:

- 93% of gynaecologists discussed their difficult cases with medical specialists in other hospitals.
- 82% of gynaecologists referred women with endometriosis to other hospitals for advice concerning diagnostics, treatment, multidisciplinary treatment or for reasons of endometriosis-associated subfertility.
- 85% of gynaecologists thought that endometriosis care should be centralized.
- 24% of gynaecologists stated that complex cases should only be treated in an expertise centre for endometriosis.

Tertiary health care setting	Reference centres for endometriosis (cf. Infra)
Care pathway for endometriosis	Care pathways for endometriosis have been developed (cf. Infra)
Initiatives to install/enhance multidisciplinary care	Regional (hospital) networks organize endometriosis care and cooperation between specialists mainly on their own initiative. Regional meetings are organized within these hospital networks to discuss endometriosis care (complex cases, evaluation/diagnosis/treatment, referral, cooperation).
Proximity of care	In the Netherlands, every citizen has access to a hospital where basic care for endometriosis is provided within approximately 50 km (mostly within 25 km). Currently, we are in the process of identifying centers of expertise. The number of centers and the geographical locations of these centers will become more clear within the coming 4 years. <i>(Personal communication with reviewer)</i>
Access to care	The importance of the GP can't be underestimated in the Netherlands for access to care, as a GP is the gatekeeper to specialist care. A study on barriers and facilitators for the timely diagnosis of endometriosis in primary care, noted that's the diagnostic process of endometriosis by GP's is hampered by a limitation in knowledge, lack of awareness, lack of appropriate guidelines and insufficient collaboration between GP's and gynaecologists.³⁸² General practitioners propose a closer collaboration with gynaecologist to improve the care offered to women with endometriosis.³⁸² The estimated time to diagnosis by GPs was 65.7 months. The time until first medical consultation at the GP office (or patient delay) was 39.1 months and the time from first GP consultation to diagnosis (or doctors delay) was 26.6 months.³⁸³ Importantly these delays reflect the opinion of the GP participating in the questionnaire.³⁸³ Gynaecologists from 67 out of 85 hospitals in the Netherlands participated in a questionnaire on diagnostic delay.³⁸⁴ Results showed that gynaecologists estimate the median time between the onset of symptoms and diagnosis to be 42 months. However, 97% mentioned an acceptable delay should not be longer than 2 years, between the start of symptoms and the diagnosis.³⁸⁴ The diagnostic process was evaluated by a questionnaire-guided telephonic interview among patients diagnosed with endometriosis in a hospital with a specialized, multidisciplinary endometriosis team.⁸ The results showed that patients waited 7 months to visit a GP, a GP referred them to a gynaecologist after 35 months and the gynaecologist needed 5 months to confirm the diagnosis of endometriosis. The median time interval from the onset of symptoms to diagnosis was thus 89 months, mainly reflecting GP delay.⁸



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Patients postpone their visit to specialized care centers and ultimately receiving the diagnosis of endometriosis, due to stigma or gender issues.¹⁴² Additionally, patients report that they often are not being heard with their complaints (no referral) or getting referred to gynaecologists without endometriosis specialization (bad referral).¹⁴²

Any other valuable information

Reference centres for endometriosis

General info

A working group of gynaecologists involved in endometriosis care (SIG), embedded in the Dutch Society for Obstetrics and Gynaecology ('Nederlandse Vereniging voor Obstetrie en Gynaecologie, NVOG'), was founded in 2009.¹⁶⁰ Based on the available literature and the results of the nation-wide survey in 2016 (cf. "Secondary health care setting"), the board of the NVOG SIG Endometriosis wrote a proposal for criteria for endometriosis expertise centers.¹⁶⁰ This proposal was reviewed by all members of the SIG and the patient association (ES, Endometriose stichting). After review the quality standard was approved by the board of the NVOG in 2020 and ready to be implemented in daily practice in June 2020 after authorization of all members of the NVOG.^{160, 204}

The developed quality standard fits within the Note Requirements Standards for Institutions ('Nota Eisen Normen voor Instellingen', NENI), which describes the requirements and standards to which health care services are held when they want to provide low-complex (category 1), complex (category 2) and high-complex care (category 3).

Who is referred to reference centres?

All patients with endometriosis or a suspicion of endometriosis can be referred to expertise centres in endometriosis by their GP, however referral by a GP is mandatory.

Licensing standards

Licensing standards are based on clinical, professional, organizational, educational and research aspects of each centre. The NVOG has formulated the minimal requirements for level-1 and level-2 centres, where a level-1 centre offers basic endometriosis care and a level-2 centre complex endometriosis care.²⁰⁴

The **criteria for the level-1 centres**, responsible for basic endometriosis care, are:

1) Clinical criteria

All surgical techniques are done by gynaecologists with a proven track-record and affinity with endometriosis surgery. Surgery can only take place in a level-1 centre, if after anamnesis, physical examination and diagnostics (echography or MRI) a high level of certainty is attained to *exclude* deep endometriosis.

Minimal surgical/medical treatments offered at a level-1 centre:

- Laparoscopic treatment of peritoneal and ovarian endometriosis:
 - o Adhaesiolysis
 - o Diathermic, plasma or laser ablation and/or excision of peritoneal and superficial endometriosis
 - o Cystectomy with as little damage to ovarian cortex as possible.
- Laparotomic excision of small abdominal wall nodules.
- Fertility treatment: at least IUI (Intra-uterine insemination) is offered, for In vitro fertilization (IVF) may be referred to another hospital.



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2) Health professional

- At least one gynaecologist, working on endometriosis, is a member of the NVOG SIG.
- At least one gynaecologist, working on endometriosis, follows postgraduate/expert education on the subject of endometriosis.

3) Organisation

- Participate at least twice a year to a regional meeting with a level-2 centre.

On top of the criteria for level 1 centres, **level 2 centres**, which are responsible for complex endometriosis care, have to fulfil the **following additional criteria**:

1) Clinical criteria

- Multidisciplinary treatment of a patient, with a multidisciplinary team of at least: gastro-intestinal surgeon, urologist, radiologist, gynaecologist.
 - o Presence of all these members is required at a multidisciplinary meeting to discuss possible surgical indication.
 - o Other members of the multidisciplinary team: gastro-enterologist, pain specialist, physiotherapist, psychologist and nurse.
- Laparoscopic treatment of deep endometriosis
- Fertility treatment: all fertility treatments are offered in the level-2 clinic. IVF may take place in a satellite setting. The fertility specialist and the gynaecologist, do not have to be the same person, but should preferably both work at the level-2 clinic.

2) Health professional

- At least 50 new patients per year.
- At least 50 surgeries for endometriosis per year, whereof at least 20 for deep endometriosis.
 - o The gynaecologist who performs the surgical interventions for deep endometriosis, has at least experience from 50 surgeries for deep endometriosis.

3) Organisation

- Registration of data in a format provided by the NVOG working group endometriosis: number of new patients, number of surgeries, complications, patient satisfaction.
- Keeping track of patient satisfaction.
- The level-2 centre organises the cooperation between level-1 and level-2 centres in regions
- The level-2 centre invites hospitals in the region to participate in the regional network of the level-2 centre

4) Education

- Differentiation internship AIOS for VPG reproductive medicine/benign gynaecology present, in which care for endometriosis patients is embedded.



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5) Research

- The level-2 centre needs to show participation in scientific research in collaboration with other centres or on own initiative.

Quality assurance	The adherence to the abovementioned licensing standards is audited by a quality committee of the NVOG every 5 years. ²⁰⁴
Dedicated funding of reference centres	NA
Legal framework	The NVOG quality standard is based on the formal norms of centralisation of complex care, i.e. the NENI-norms* ("Nota Eisen normen voor instellingen"). Level-1 centres are mentioned as complex care (category 2 in NENI-norms) and level-2 centres are mentioned as highly complex care (category 3 in NENI-norms). <i>NENI-norms: note that defines the requirements and norms that institutions need to adhere. These norms and requirements are described to ensure quality and safety of care.</i>
Is there a liaison between reference centres and the primary and secondary level?	Level-1, level-2 centres and surrounding hospitals are organised in regional networks with regional meetings. ²⁰⁴ This organisation model of regional networks, is part of the licensing standards set up by the NVOG and level-2 centres are considered to take the initiative to organise the collaboration within their region. ²⁰⁴
Public reporting/Published evaluation of the reference centres?	An annual survey is sent out by the patient association ("Endometriose stichting") to each (candidate) level-1 or level-2 endometriosis centre.²¹⁰ This survey collects information on the organisation of care and level of individual expertise, along with: - The amount of newly referred patients per year - The total number of consultations per year - The average duration of the first consult - Type of surgeries conducted at the centre - Type of fertility treatments available at the centre - The composition of the multidisciplinary team - A list of centres with whom the centre has agreed to collaborate and/or refer patients - List of types of information that are provided to the patient after receiving the diagnosis of endometriosis (e.g. folders, personal explanation, referral to website or patient organisations,...) The results of this survey, latest available report from 2019 due to COVID, are published on the website of the patient association and a summary report is published on the website of the NVOG.^{210, 211}
Any other valuable information	Questionnaires on quality of life were disseminated among patients in a secondary and two tertiary clinics in the Netherlands between 2011 and 2016. ^{261, 385, 386} These have shown that communication, information, and education were identified as an important improvement targets for endometriosis clinics. Often patients evaluated this domain negatively, although they found this very important. ^{261, 385, 386}
Recognition of endometriosis as a chronic condition	



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Is endometriosis recognised as a chronic condition? No³⁸⁷

Licensing standards NA

How is the recognition installed? NA

Consequences for patients NA

Consequences for the health care setting NA

Funding NA

Evaluation of endometriosis being recognised as a chronic condition NA

Any other valuable information For endometriosis no dedicated guideline or protocol has been developed for the Employee Insurance Administration ('Uitvoeringsinstituut werknemersverzekeringen', UWV).³⁸⁷ In other words, the diagnosis of endometriosis does not imply being incapable of working. If endometriosis causes disability, insurance doctors of the UWV will evaluate the caused disability on an individual basis.³⁸⁷

Endometriosis registry

Is there an endometriosis registry? No, but structural information is gathered by the patient association ("Endometriose Stichting") with an annual online survey that is sent to 25 hospitals, since 2015.²¹⁰ All hospitals who aim to be a level 2 center of expertise have their own registry, as expected in the annual report, that is requested from level 2 centers. But there is no national registry yet. (personal communication with reviewer)

Who is in charge? NA

Legal framework NA

Funding NA

Criteria NA

Coverage NA

Data collected? This annual survey (2019) has collected data on the following subjects of the 22 participating hospitals.²¹¹

- The amount of newly referred patients & consultations per year:
 - o For all 22 hospitals: 4 941 endometriosis patients per year
 - o On average 20 to 500 endometriosis patients per year per centre (new diagnosis and second opinions)
 - o 1 976 patients with extended or deep endometriosis (39.8%)



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- The average duration of the first consult:
 - o 30-45 minutes
- Type of surgeries conducted at the centre:
 - o All centres conducted surgical interventions for endometriosis
 - o In total 1 555 surgical interventions
 - o On average 10 to 240 surgical interventions per year (most commonly laparoscopy)
 - o List of detailed surgical interventions performed at each centre
 - o 17 hospitals could provide deep endometriosis surgery numbers, they are responsible for 961 deep endometriosis surgeries per year
- Type of fertility treatments available at the centre
- The composition of the multidisciplinary team
- A list of centres with whom the centre has agreed to collaborate with and/or refer patients to

Results	NA
Any other valuable information	/
Guidelines and quality indicators	
Guidelines	The Dutch Society for Obstetrics and Gynaecology (NVOG) is deemed responsible for national updates and dissemination of the ESHRE guideline in primary and secondary care. ³⁸⁸
Quality indicators	No (standardized) quality indicators are collected, level 2 expertise centres collect annually data on patient satisfaction to rate their quality of care.
Care pathway for endometriosis	No national implemented care pathway for endometriosis exists, some hospitals are developing regional pathways to improve endometriosis care.
Any other valuable information	Some reference hospitals provide a care path on their website to inform patients what to expect before their consultation at the clinic. ³⁸⁹
National action plan on endometriosis	
National action plan on endometriosis	No
Key actions	NA
Evaluation	NA
Funding	NA
Any other valuable information	Policy makers state that endometriosis is high on the priority list of NVOG and that the focus should be on raising awareness among patients and health professionals (education & following clinical guidelines in primary and secondary care). ³⁸⁸ This is seen as a task for professional associations and the educational system (patients & professionals). ³⁸⁸



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Training about endometriosis

Training on endometriosis during the professional curriculum of primary care professionals

GPs in training receive a short theoretical module on gynaecological problems in which endometriosis is scarcely addressed. The curriculum is under responsibility of the Ministry of education, culture & science ("ministerie van onderwijs, cultuur en wetenschap", OCW).

In the training of a general practitioner, a module can be followed to acquire specific expertise in gynaecology, one of the subjects being urogynecology (which includes the subject of endometriosis). However, this training lasts a maximum of three months and is not compulsory for every GP.

A questionnaire study among general practitioners on their knowledge of endometriosis revealed that 76 out of 87 GPs stated they need further education on endometriosis.³⁸³

Training on endometriosis during the continuing medical education of primary care professionals

Less than 0.5% of GPs in the Netherlands have completed special training in women's health. GPs reported limited training, experience and knowledge about endometriosis (both in internships and educational programmes).³⁸²

Level-2 centres are obligated, according to the NVOG licensing standards, to provide expert training for general practitioners and medical specialists in their region.²⁰⁴

Other initiatives to improve the knowledge on endometriosis among primary care professionals

Training on endometriosis during the professional curriculum of medical specialists involved in endometriosis care

The subject of endometriosis is included in the professional curriculum of medical specialists:

- **Year 1-2 (with supervision) and year 2-4 (without supervision)**
 - o Diagnostics & conservative treatment of endometriosis
- **Year 6 – differentiation module**
 - o Pharmacological and surgical treatment of endometriosis (Reproductive medicine – Differentiation : fertility-promoting surgery)
 - o Conservative treatment of endometriosis (Benign gynaecology – Differentiation gynaecology)

Training on endometriosis during the continuing medical education of medical specialists (involved in endometriosis care)

Level-2 centres or hospitals with more expertise in endometriosis care provide continued education to gynaecologists focused on endometriosis and fertility.

The NVOG organises educational days for gynaecologists to improve awareness, expertise, cooperation and uniformity in treatment. The NVOG also developed a quiz with knowledge questions about endometriosis (based on the ESHRE-guideline) for medical specialists. Medical specialists were free to sign up to receive these questions (weekly – monthly) and received accreditation points, when they signed up for this initiative.

Other initiatives to improve the knowledge on endometriosis among medical specialists

Professionals (at least one) working in level 2 centres are obligated to be a member of the working group endometriosis.²⁰⁴

Level-2 centres are also obliged to provide the differentiation module/stage (year 6) to improve training and education.²⁰⁴

Any other valuable information



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Awareness about menstrual health and endometriosis

Education on menstrual health	Primary and secondary schools offer sexual education, but are free to decide which program(s) or methods they follow. Several (educational) websites and initiatives are aimed to specifically reach adolescents to promote menstruation welfare and awareness. For example: websites (www.ongewoonongesteld.nl , sense.info , GirlsTalk.Period!) and social media campaigns. ³⁹⁰
Education on endometriosis	Primary and secondary schools are free to decide the program or methods of education on sexuality, health and relations. An available educational package for schools has been developed by one of the endometriosis patient association ("Endometriose stichting").³⁹⁰ Patients with (a suspicion of) endometriosis are pointed towards several websites with scientific information on endometriosis and menstrual health, such as: - www.degynaecoloog.nl - www.ongewoonongesteld.nl - www.endometriose.nl Several initiatives have been set up by patient associations (such as the Endometriose Stichting, Belangengroep endometriose, Freya,...) to provide patients with information on endometriosis, such as (online) support groups (ex. Endolounges, buikspreker), webinars, podcasts and closed forums/groups on social media.³⁹⁰ Patients, relatives and/or professionals are referred to websites such as: - www.Thuisarts.nl - www.endometriose.nl - www.degynaecoloog.nl - www.NVOG.nl These websites offer possibilities and initiatives to recognize the symptoms associated with endometriosis through information, (online) questionnaires and self-tests for patients, relatives and/or professionals.
Awareness campaigns on endometriosis (laymen)	Patient and support organisations raise awareness about endometriosis in the general public through various initiatives (ex. Endometriosis awareness month, (online) events, presentations and articles). ³⁹¹
Awareness campaigns on endometriosis (health professionals)	The patient association Endometriose Stichting, raises awareness about endometriosis in health professionals through cooperation with the professional groups (NVOG,...), webinars, articles in (scientific) journals, attending scientific conventions and presentations at different levels (primary care, specialists,...).^{391, 392} Besides these meetings, other regional or hospital initiatives exist to improve the information exchange and transparency between experts and patients (ex. Online platform, Zorgwijzer).
Any other valuable information	Policy makers are convinced that there is enough information available but the lack of awareness/education is more because how it is implemented/educated in practice.³⁸⁸ Some centres have developed tools to guide patients through their care path:

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- A specialised hospital in Den Haag ("Endometriosis in balans") has developed a Patient Journey App which accompanies a patient through the care path.³⁹³
- The VUmc & AMC in cooperation with the patient organisation have developed a tool to guide endometriosis patients to retain their fertility through the disease.

Any remaining thoughts, suggestions, comments, ...

/

Appendix 5.9. Organisation of endometriosis care in the United Kingdom

The content provided in Table 46 was reviewed by Dr. Andrew Kent (President BSGE), Dr. Arvind Vashisht (Vice President BSGE) and Mrs. Gilly MacDonald (Endometriosis nurse specialist representative).

Table 46 – Organisation of endometriosis care in the United Kingdom

Country: UK	
General information	
The health care system	National Health Services (NHS) in the United Kingdom (UK) is devolved into four separate NHS: England, Wales, Scotland and Northern Ireland.³⁹⁴ Each of these has their own planning and monitoring frameworks and public health agencies. The system is tax-funded (in all regions). Money is allocated by the central UK government for health care and block grants are provided for this to the separate nations, which then set their own health budgets and priorities. The NHS provides universal access to a comprehensive package of services, mostly free at the point of use. Accessibility is therefore good, although waiting times are a (major) problem. There is also a private healthcare sector, and private health insurance can be purchased.³⁹⁴ Primary care is provided by teams of general practitioners (GPs), nurses and sometimes other health professionals; most GPs are self-employed and contracted to provide services in the NHS (59.4%); an increasing proportion of GPs are employed in practices on a salaried basis (currently at 22%).²⁸⁷ GPs act as gatekeepers for secondary care. Secondary care is organized in NHS hospitals; specialists are generally salaried employees of NHS hospitals.²⁸⁷ Tertiary care services tend to be offered in larger teaching hospitals, with a trend towards fewer, more specialised centres.³⁹⁴
Period of data collection	August - November 2023
Endometriosis in the UK	



Country: UK

Prevalence of endometriosis

The reported prevalence in many sources is 3%-10% of women aged 15-45 years.^{71, 395} The oft-reported prevalence of “up to 10%” of women being affected by endometriosis traces back to old cohort studies on surgical patients, which could have biased prevalence figures upwards.⁷⁰

A study performed in the general UK population from 2017 reviewed diagnostic codes and medical records (covering the period of 2000-2010) and found a prevalence of only 2.1% among women aged 12-54 years in 2010 and an incidence of 1.46 per 1000 person-years.³⁹⁶ This study aimed to be complete by not only including women with a diagnostic code for endometriosis, but also by reviewing medical records of a random subset of women with a diagnostic code for dysmenorrhoea or hysterectomy and by sending out questionnaires to a subset of these women or their GPs. Information on possible endometriosis gathered in this way was then extrapolated to the whole population with these diagnostic codes. This led to an additional identification of 2514 endometriosis cases, 35% of the total number of cases.³⁹⁶ This estimate may be an underestimation as some women may not have sought medical care for complaints such as dysmenorrhoea.

A recent prospective cohort study performed transvaginal ultrasound in premenopausal women (n = 1026) attending a general gynaecology clinic.⁷⁷ They found a very high prevalence of 18.9% of women having sonographic evidence of deep and/or ovarian endometriosis. This population is however not representative for the general premenopausal population, as the included population consulted the clinic for gynaecological symptomatology, often related to endometriosis.⁷⁷

Organisation of endometriosis care

Primary health care setting

The Royal College of General Practitioners (RCGP) developed an online Menstrual Wellbeing Toolkit for GPs, as part of their Women's Health Hub. This contains, among others, “Top tips for managing endometriosis in primary care”.²²⁸

These were adapted from “Top Tips” developed by Primary Care Women's Health Forum, which in turn are mainly based on the National Institute for Health and Care Excellence (NICE) guideline.^{2, 397}

Patients need a referral to the secondary level by a GP.²⁸⁷

The endometriosis clinical pathway (cf. infra) is aimed at the primary care level.

Secondary health care setting

Patients can be referred to Gynaecology services, which serves as secondary health care level, by their GP.²⁸⁷ There are no specific resources aimed at secondary care level, except for the NICE guidelines.²

Referral from secondary to tertiary care level appears not to be straightforward; in a 2022 survey by Endometriosis UK in Scotland, interviews were held with secondary care providers (n=23), in which they claimed: “In terms of referring patients on to other services, of the non-specialist gynaecologists surveyed, most struggle to access endometriosis specialist gynaecologists (61%, n=14).”³⁹⁸

Tertiary health care setting

Accredited endometriosis centres (cf. infra)

Care pathway for endometriosis

Cf. infra

Initiatives to install/enhance multidisciplinary care

The NICE guideline for endometriosis recommends multidisciplinary care centres in second and third line.²

This has not been structurally implemented yet in second line.⁷¹

**Country: UK**

For third line care (the endometriosis accredited centres), multidisciplinary care is among the requirements for accreditation (cf. infra).

Proximity of care

No specific policies found

Access to care

According to the All-party parliamentary group (APPG) report on endometriosis, patients experienced endometriosis care as **untimely** and they found **referral was often inadequate** (e.g. referred first to a general gynaecology service without knowledge on endometriosis).⁷¹ The data for this report were obtained by performing a patient survey on a self-selecting sample of 10,783 endometriosis patients. In addition, four interview sessions were held with patients and healthcare practitioners.

Of the surveyed patients, 21% needed 10 or more visits to doctors in hospital before receiving a diagnosis. Only 19% of surveyed patients knew whether they had been seen in an accredited centre. Prior to covid-19, 30% of patients in the UK were waiting > 10 months for surgery, with large regional differences (13% in Scotland, 17% in England, 32% in Wales and 42% in Northern Ireland).⁷¹

During the pandemic, gynaecology services experienced increased waiting lists (60% increase over three years).³⁹⁹ Endometriosis UK, a patient organization, organized a survey in May 2021 on the impact of Covid-19 on endometriosis care and received > 1500 responses.³⁹⁹ According to this survey, respectively 91% and 90% of respondents experienced more difficulty to obtain surgery and gynaecology centre appointments. Appointment were cancelled or postponed in 80% of respondents, of which 35% had not yet been given a new date at the moment of the survey.³⁹⁹

Any other valuable information**Reference centres for endometriosis****General info**

The Endometriosis Centres project was initiated in 2008, by the BSGE, and was realised with NHS commissioning in 2013.²⁰⁵ At present there are 34 NHS commissioned centres and 76 BSGE accredited centres with 11 provisional centres (as at April 2023). (*personal communication with reviewer*;⁴⁰⁰) Some centres are both NHS commissioned and BSGE accredited but not all. Centres who wish to achieve BSGE accreditation must register first as "Provisional endometriosis centres", during which time they can work towards the requirements for accreditation; once they are audited by the British Society for Gynaecological Endoscopy (BSGE) (each year in December), they can be accredited.¹⁶¹ Accreditation is reviewed annually. Wales and Scotland both have only 4 accredited centres, while Northern Ireland appears to have none at the moment.⁴⁰⁰ This discrepancy in access to accredited specialist centres between the regions was also highlighted in the APPG report.⁷¹

Accredited centres who fall below the 12 required cases per gynaecological surgeon per year will move from Accredited Centre to Provisional Centre. If they fail in the following year to get to 12 cases, they are removed from the list.²⁰⁶

The current accreditation/commissioning process is recognised as having served its purpose but is outdated. (*personal communication with reviewer*) The NHS Service Specification for Complex Gynaecology Severe Endometriosis is currently under review jointly by National Health England Clinical Reference Group and the BSGE. It is envisaged that a revised service specification and commissioning process will be in place within 2 years (2025) allowing for transition. (*personal communication with reviewer*)

Who is referred to reference centres?

The NICE guideline states that all women with suspected or confirmed "deep" endometriosis (involving bowel, bladder or ureter) should be seen in an endometriosis specialist centre.²

**Country: UK**

Estimations of the prevalence of deep endometriosis are usually around 1% of the female population of reproductive age.⁴⁰¹ This would amount to 10-20% of endometriosis patients, depending on the prevalence of endometriosis. A recent prospective study in women attending a gynaecology clinic (for any gynaecological symptoms, not specifically endometriosis) found a prevalence of deep endometriosis as diagnosed by ultrasound of 18.9% of premenopausal women (cf supra).⁷⁷

Other endometriosis patients can be managed at secondary care, by a gynaecologist with interest and special training in endometriosis and pelvic pain.² This level is not formally implemented in the UK, according to the APPG report.⁷¹

Licensing standards

The following criteria were taken directly from the BSGE website :¹⁶¹

1. Dedicated consultant-led endometriosis service run within a specialist outpatient clinic. This clinic must be specifically dedicated to endometriosis treatment, and should be named Endometriosis clinic to increase visibility to patients. A lead consultant or team of consultants run the service.
2. At least 12 surgeries for rectovaginal endometriosis (requiring dissection of the pararectal space) are performed per surgeon each year (the requirement of minimum number of surgeries **per surgeon** was added in 2017).
3. These procedures must be recorded in the BSGE database and followed up for 2 years post-surgery.
4. A colorectal surgeon is required to support the service; he/she will attend complex surgery involving the bowel.
5. A support network is required including urologists and pain management specialists providing active support.
6. Since 2014, an endometriosis specialist nurse is required, carrying out primary patient contacts and triage.
7. Submission of an exemplar video of surgery for laparoscopic excision of severe recto-vaginal endometriosis (since 2016). This video must be submitted yearly; its purpose is to ensure that cases entered into the endometriosis database are consistent with BSGE expectations

Quality assurance

The centres are reviewed yearly in December by BSGE for accreditation the following year.²⁰⁶

Dedicated funding of reference centres

Endometriosis clinics are funded through NHS, following the NHS standard contract for complex gynaecology – severe endometriosis.³⁹⁵ This contract provides a framework for the requirements of BSGE to be met, although BSGE accreditation is not entirely aligned with commissioning by NHS (a centre can be specially commissioned for endometriosis care but not accredited). The requirements for both are however very similar. (*personal communication with reviewer*)

Legal framework

Cf. supra

Is there a liaison between reference centres and the primary and secondary level?

No direct liaison found, but the “Top Tips” of the Primary Care Women's Health Forum, aimed at UK general practitioners, refers specifically to the BSGE specialist centres for surgical management of severe endometriosis.³⁹⁷ This explicit referral to endometriosis reference centres was unfortunately not included in the Top tips for managing endometriosis in primary care section of the Menstrual Wellbeing Toolkit of the RCGP.²²⁸

Public reporting/Published evaluation of the reference centres?

There are no audit reports or other evaluations of the endometriosis centres available at present. (*personal communication with the reviewer*) In 2018, an analysis of the BSGE dataset was published by Byrne et al.²¹⁵ (cf. infra for details)

The annual number of surgeries per accredited centre can be found on the BSGE website.²¹²

Any other valuable information



Country: UK	
Recognition of endometriosis as a chronic condition	
Is endometriosis recognised as a chronic condition?	It is not formally recognised as a chronic condition. ⁷¹
Licensing standards	NA
How is the recognition installed?	NA
Consequences for patients	NA
Consequences for the health care setting	NA
Funding	NA
Evaluation of endometriosis being recognised as a chronic condition	NA
Any other valuable information	
Endometriosis registry	
Is there an endometriosis registry?	Yes; since 2007. ²⁰⁵ It is not publicly accessible but is managed by BSGE. ⁴⁰² The annual number of surgeries per accredited centre can also be found on the website. ²¹²
Who is in charge?	BSGE
Legal framework	Contribution to the register is a requirement to be a BSGE accredited centre. ¹⁶¹ The NHS commissioned contract for endometriosis care also has patient registry as a quality indicator, ³⁹⁵ but this is not enforced to the best of our knowledge. (<i>personal communication with reviewer</i>)
Funding	The register is funded by BSGE. ²⁰⁵ The BSGE itself is a “charitable organisation” and is funded mainly through membership fees and income through conferences and courses. ⁴⁰³
Criteria	Only surgical cases of rectovaginal disease are included in the register, more precisely, the dissection of the pararectal space was taken as discriminating factor. ¹⁶¹
Coverage	Restricted to those treated in accredited centres
Data collected?	Outcome data on pain, bowel function and symptoms, quality of life (QoL) and complications assessed prior to surgery and then at 6 months, 12 months and 24 months post-surgery; QoL assessed by questionnaires (EuroQol 5D-3L questionnaire and EuroQol Visual Analogue Score); type of surgery performed; other medical treatments; surgical complications. ²¹⁵

**Country: UK****Results**

The BSGE published an analysis of the data from the registry in 2018 (data collection: January 1st 2009 to June 30th 2016).²¹⁵ Between 1 January 2009 and 30 June 2016, 5 162 women underwent surgery for deep rectovaginal endometriosis in one of the BSGE Endocentres. Overall results were good, although follow up in terms of QoL data was limited when all centres were taken into account (47% at 6 months, 38% at 12 months, 24% at 2 years). There were significant reductions in endometriosis-related pain at 6 months post-surgery which were sustained at 2 years. Voiding difficulty, bowel frequency, urgency, incomplete emptying, constipation and passing blood also showed improvement, all of which were maintained at 2 years with the exception of voiding difficulty. Global quality of life also improved from a median pre-treatment score of 55/100 to 80/100 at 6 months. There was no control group of patients with endometriosis not treated in a BSGE Endocentre.²¹⁵ Similar surgical and QoL outcomes up to 1 year were found in a publication an NHS commissioned centre (Guildford) which included patient with severe rectovaginal disease operated on by a combined gynaecology/colorectal team.⁴⁰⁴ We could not find regular reports on quality of provided endometriosis services or other analyses from the BSGE register.

Any other valuable information

The initial provider for the web-based database to store the data proved to be unsuitable, hence another provider was selected. Structure and content of the database was an enormous task (cf. website BSGE) and continuous improvement and refinement were necessary.²⁰⁵

Guidelines and quality indicators**Guidelines**

There are NICE guidelines (2017), which are not enforced or imposed.²

Quality indicators

Quality statements & indicators have been defined by NICE in their Endometriosis Quality Standard, based on the 2017 guideline; the quality standard was published in 2018.⁴⁰⁵ These indicators are not audited nationally but would form part of local hospital guidance / treatment pathways.

These quality indicators are the following:

Quality statement 1: women presenting with suspected endometriosis have an abdominal and, if appropriate, a pelvic examination.

- Structure indicator:
 - o evidence of local arrangements to identify women with signs/symptoms of endometriosis
 - o evidence of protocols detailing symptoms of endometriosis and the need for examination when suspected
- Process indicator: proportion of women who present to healthcare professionals with symptoms/signs suggesting endometriosis who have an abdominal/pelvic examination
- Outcome indicator:
 - o number of working diagnoses of endometriosis following initial presentation
 - o time from initial presentation to diagnosis

Quality statement 2: Women are referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated

- Structure indicator: evidence of local referral pathways to gynaecology services
- Process indicator: proportion of women in whom initial hormonal treatment is not effective after 6 months, who are referred to a gynaecology service

**Country: UK**

- Outcome indicator: satisfaction of women with endometriosis with their treatment plan

Quality statement 3: Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service.

- Structure indicator:
 - o Evidence of local referral protocols for women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.
 - o Evidence of services working toward accreditation as specialist endometriosis services.
- Process indicator: Proportion of women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter who are referred to a specialist endometriosis service.
- Outcome indicator:
 - o Diagnosis rates of deep endometriosis involving the bowel, bladder or ureter.
 - o Rates of surgical treatment for deep endometriosis involving the bowel, bladder or ureter by specialist endometriosis services.⁴⁰⁵

In its contract for centers for specialized care in severe endometriosis, the NHS has also defined quality standards (n=11).³⁹⁵ These are currently not followed up by NHS. There was a proposed national peer review process pre-Covid, but this was deferred. There are current plans to revamp service specification which will address this. (*personal communication with reviewer*)

- > 70% of cases entered into the BSGE register
- Compliance with BSGE criteria for laparoscopic surgery for severe endometriosis for all cases
- Quality of life median score improvement by at least 20% 2 years after surgery
- >75% of cases record standard dataset of patient symptoms on national database for audit
- Ensure adequate follow up of > 75% of surgical cases for severe endometriosis
- >50% proportion of patients completing anonymous feedback questionnaire
- >90% of patients have surgery within 18 weeks of referral to specialist centre
- >90% of patients are given date for surgery at least 4 weeks in advance
- <10% of patients have surgery date changed once issued
- Confirmation of two skilled laparoscopic surgeons for all cases
- All surgery to be undertaken in theatres designed to undertake complex laparoscopic surgery

Care pathway for endometriosis

There is a care pathway for endometriosis, aimed at the primary care level; version 2 was published in March 2019.¹⁹⁶

Any other valuable information

A survey among practitioners in Scotland revealed that of gynaecologists not specialized in endometriosis (n=36), 47% (n=17) were familiar with the guideline and its recommendations and 50% (n=18) were aware of the guideline but not the details.³⁹⁸ Of these practitioners, 39% (n=14) believed Scotland was somewhat meeting the Guideline and Standards, whereas 17% (n=6) believed the Guideline was not being met in Scotland. Only 6% (n=2) felt that Scotland was meeting the Guidelines and standards well.³⁹⁸

National action plan on endometriosis



Country: UK	
National action plan on endometriosis	No
Key actions	NA
Evaluation	NA
Funding	NA
Any other valuable information	NA
Training about endometriosis	
Training on endometriosis during the professional curriculum of primary care professionals	Not assessed
Training on endometriosis during the continuing medical education of primary care professionals	BSGE organizes Endometriosis CNS (Clinical Nurse Specialists) Education days and BSGE Nurse Hysteroscopy Operative Workshops. ⁴⁰⁶
Other initiatives to improve the knowledge on endometriosis among primary care professionals	The Royal College of General Practitioners (RCGP) developed an online Menstrual Wellbeing Toolkit for GPs, as part of their Women's Health Hub. This contains, among others, "Top tips for managing endometriosis in primary care" ²²⁸
Training on endometriosis during the professional curriculum of medical specialists involved in endometriosis care	Curriculum for advanced surgical training for endometriosis (RCOG ATSM). <i>(personal communication with reviewer)</i>
Training on endometriosis during the continuing medical education of medical specialists (involved in endometriosis care)	BSGE organizes/supports several continuing medical education activities for specialists, such as the Gynaecological Applied Pelvic Anatomy Revision Course, RCOG/BSGE Benign Abdominal Surgery course; RCOG/BSGE Diagnostic and Operative Hysteroscopy Meeting; the Advanced Gynae Laparoscopic Simulation Course; and BSGE Nurse Hysteroscopy Operative Workshop. ⁴⁰⁶ The Royal College of Obstetricians & Gynaecologists offers an advanced training module in obstetrics & gynaecology, which covers, among others, the laparoscopic excision of superficial and deep infiltrating endometriosis. ²³⁰
Other initiatives to improve the knowledge on endometriosis among medical specialists	Not assessed
Any other valuable information	Clinical Nurse Specialists: There are clinical nurse specialists (CNS) in endometriosis in the UK, assisting in the accredited centres (requirement for accreditation since 2014). ¹⁶¹

**Country: UK**

Requirements to become a specialist nurse are a qualification as registered nurse, an initial registration with the Nursing and Midwifery Council and (depending on the specialty) a period of experience in specialized practice.²⁰⁷ According to a factsheet issued by the Royal College of Nursing (RCN), there is a consensus in the UK that specialist nurses should also have completed a 1 year full-time degree level programme involving 50% theory and 50% practice. It is not clear whether this is enforced to be able to claim the title of CNS.²⁰⁷

There is also a RCN Skills Framework, which specifies that CNS should have a master degree and display masters level thinking and decision making.⁴⁰⁷ Skills specifically required for a CNS in endometriosis, divided into core competencies and desirable competencies, have been described by the BSGE. (*Gilly MacDonald, personal communication*)⁴⁰⁷ Education and mentoring of these nurses is provided by the BSGE. (*Gilly MacDonald, personal communication*)

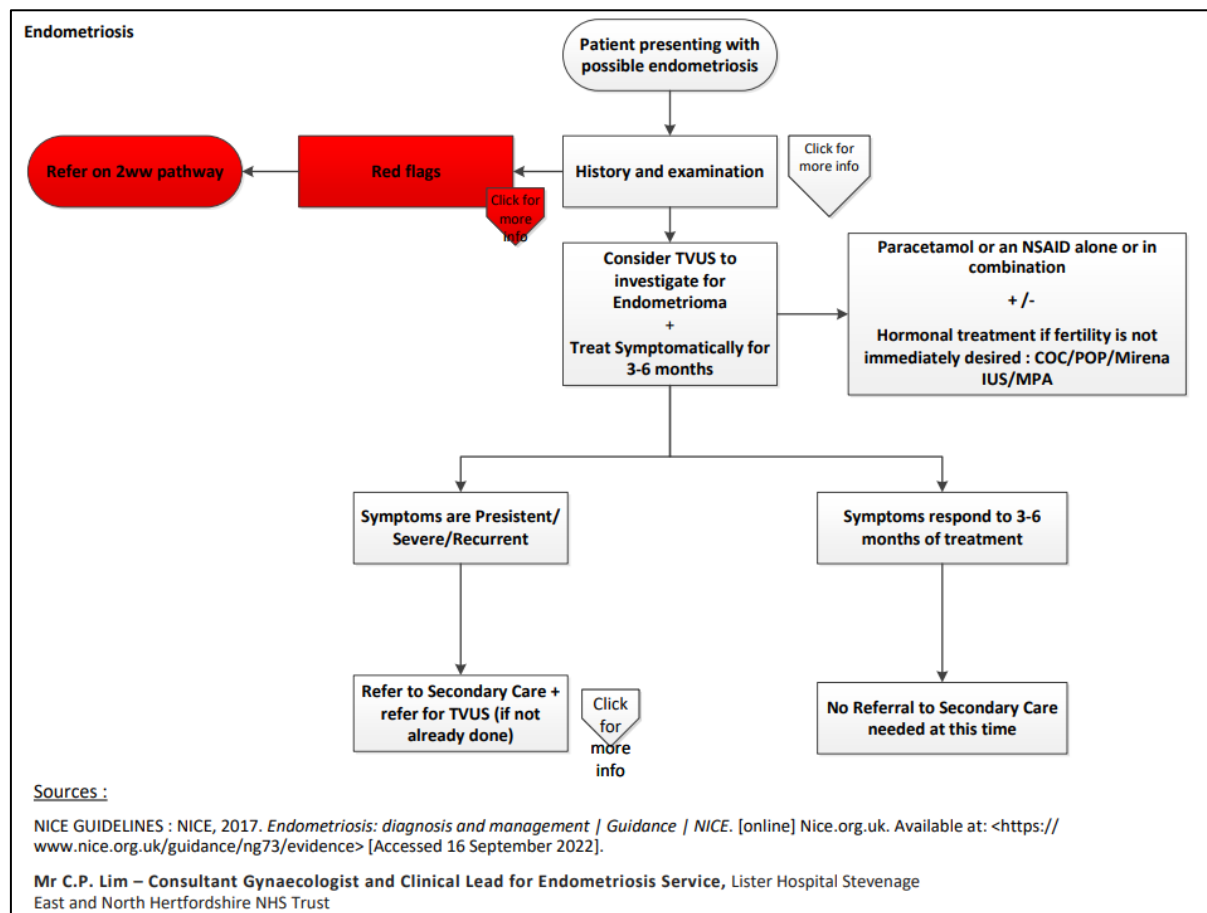
In 2017, a survey was sent out to 66 endometriosis specialist nurses, working in 58 accredited endometriosis care centres (all accredited centres at the time).⁴⁰⁸ The survey showed that most endometriosis nurse specialists (87%) had another nursing role alongside their endometriosis role. Despite recommendations in the RCN Skills Framework specifying Master's level functioning of RCN, only 11 (29%) of the respondents were educated to Master's level. There is no national standard to define this role.⁴⁰⁸

Awareness about menstrual health and endometriosis

Education on menstrual health	Since 2020, menstrual wellbeing is included in the new Relationship & Sex Education curriculum and will be compulsory to teach all children in both primary and secondary education. ⁴⁰⁹
Education on endometriosis	Not found
Awareness campaigns on endometriosis (laymen)	Endometriosis Action Month (March 2023); this is a global awareness initiative which was led in the UK by Endometriosis UK. ⁴¹⁰ It was unclear from the website which activities had been undertaken exactly for this purpose.
Awareness campaigns on endometriosis (health professionals)	Menstrual health tool for GPs with Top Tips for managing endometriosis (cf. supra).
Any other valuable information	



Figure 14 – Care pathway for endometriosis in primary care - UK



Back to pathway

Red flags

- Suspicious-looking cervix
- Suspicious vulval lesion
- Suspicious vaginal mass

**History and examination****History:**

- Chronic pelvic pain
- Painful Periods (Dysmenorrhoea) with or without heavy menstrual bleeding
- Deep dyspareunia
- Dyschezia (pain on opening the bowels during and/or just preceding a menstrual period)
- Proctalgia fugax (A severe shooting pain in the ano-rectum that is most noticed at the time of opening bowels)
- Cyclical bladder or bowel symptoms
- Subfertility associated with the above symptoms

Take into account their circumstances, symptoms, priorities, desire for fertility, ADLs, work and study, cultural background and their physical, psychosexual and emotional needs. Discuss keeping a pain and symptom diary

Examination:

- Abdominal masses
- Tender nodularity in the vaginal fornices
- Visible vaginal endometriosis

**Referral to general gynaecology for diagnostic services. NB: Criteria for referral to the specialist endometriosis clinic see [click for more info](#)**

Refer to general gynaecology clinic unless patient has one of the following :

Referral criteria to Endometriosis Hertfordshire

- **Refer the following women to Endometriosis Hertfordshire: Specialist Endometriosis Clinic and considered for Endometriosis MDT discussion:**
 - Where diagnosis has been made in secondary care and initial management strategy at the discretion of the general gynaecologist is felt to be not effective, not tolerated or is contraindicated.
 - Where diagnosis remains uncertain from clinical assessment or initial laparoscopy
 - Where it is felt to be more appropriate for an endometriosis specialist to perform the initial laparoscopy
 - Where a period of hormonal suppression has improved symptoms despite having had a negative laparoscopy, but the woman seeks alternative treatment options and a second opinion is deemed appropriate
 - Women wanting a hysterectomy as treatment of endometriosis
 - When considering surgical treatment of symptomatic endometrioma ≥ 3 cm in a woman aged ≥ 35 years who desires future fertility
 - Where there is evidence (radiologically or by clinical assessment) of deep infiltrating endometriosis
 - Where there may be involvement of other pelvic organs like bladder, bowel, and ureter
 - Where there is a suspicion of endometriosis outside of the pelvis e.g. thoracic endometriosis
 - Women with suspected endometriosis aged ≤ 17 years
 - Women who require use of GnRH analogues for the treatment of endometriosis for more than 6 months without longer term definitive plan in place

Source: Lim C. 2019. *Clinical pathway Endometriosis (NHS)*¹⁹⁶



APPENDIX 6. GUIDELINES & QUALITY INDICATORS ON ENDOMETRIOSIS

Appendix 6.1. Guidelines on the diagnosis and management of endometriosis

Table 47 – Guidelines on the diagnosis and management of endometriosis (published from 2013 onwards)

Date	Institution/authors	Title of the guideline
2022	European Society of Human Reproduction and Embryology (ESHRE)	ESHRE guideline: Endometriosis ³³ (first edition: Kennedy, et al., 2005; ⁴¹¹ second edition: Dunselman et al., 2014 ³⁴)
2022	Harada et al.	Clinical practice guidelines for endometriosis in Japan (3rd edition) ⁴¹²
2022	Horn et al.	S2k [§] Guidelines for the diagnosis and treatment of endometriosis - Recommendations for pathology ⁴¹³
2021	German Society of Gynaecology and Obstetrics (DGGG), Austrian Society for Gynaecology and Obstetrics (OEGGG), Swiss Society for Gynaecology and Obstetrics (SGGG)	Diagnosis and Treatment of Endometriosis ³⁷⁹
2021	Zhonghua et al.	Guideline for the diagnosis and treatment of endometriosis in China (Third edition) ⁴¹⁴
2020	Hirata et al.	Clinical practice guidelines for the treatment of extragenital endometriosis in Japan, 2018 ⁴¹⁵
2018	Hwang et al.	Clinical evaluation and management of endometriosis: guideline for Korean patients from Korean Society of Endometriosis ⁴¹⁶
2017*	National Institute for Health and Care Excellence (NICE)	Endometriosis: diagnosis and management ²
2017	Haute Autorité de santé (HAS) - Collège National des Gynécologues et Obstétriciens Français (CNGOF)	Prise en charge de l'endométriose ²²⁷
2017	Bazot et al.	European society of urogenital radiology (ESUR) guidelines: MR imaging of pelvic endometriosis ⁴¹⁷



Date	Institution/authors	Title of the guideline
2014	Practice Committee of the American Society for Reproductive Medicine	Treatment of pelvic pain associated with endometriosis: a committee opinion ⁴¹⁸
2013	World Endometriosis Society (WES)	Consensus on current management of endometriosis ¹⁶²

**: Updates on the topics 'Diagnosing endometriosis' and 'Surgical management if fertility is a priority' are in progress and expected to be published in spring 2024. \$: S2k indicates that the guideline is consensus based.*

Appendix 6.2. Quality appraisal of the ESHRE guideline

Table 48 – AGREE II scores for the ESHRE guideline (2022)

Title	Standardised Score (%)						Final Appraisal
	Scope	Stakeholder involvement	Rigour of development	Clarity	Applicability	Editorial Independence	
European Society of Human Reproduction and Embryology (ESHRE). ESHRE guideline: endometriosis; 2022. ³³	75.0	77.8	74.0	86.1	39.6	91.7	Good



Appendix 6.3. Quality indicators for endometriosis

Table 49 – Quality indicators derived from the ESHRE guidelines (2014, 2022)

Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
Clinicians should, in all women with endometriosis		
Diagnosis of endometriosis		
i) Consider the diagnosis of endometriosis in the presence of gynaecological symptoms such as: dysmenorrhea, non-cyclical pelvic pain, deep dyspareunia, infertility and fatigue in the presence of any of the above – GPP <i>ESHRE 2022:</i> <i>The GDG recommends that clinicians should consider the diagnosis of endometriosis in individuals presenting with the following cyclical and non-cyclical signs and symptoms: dysmenorrhea, deep dyspareunia, dysuria, dyschezia, painful rectal bleeding or haematuria, shoulder tip pain, catamenial pneumothorax, cyclical cough/haemoptysis/ chest pain, cyclical scar swelling and pain, fatigue, and infertility - GPP</i>	/	Not measurable
ii) Consider the diagnosis of endometriosis in women of reproductive age with non-gynaecological cyclical symptoms (dyschezia, dysuria, haematuria, rectal bleeding and shoulder pain) – GPP <i>Not (separately) in ESHRE 2022 (included in other recommendation, cf. supra)</i>	/	Not measurable
iii) Perform transvaginal sonography to diagnose or to exclude an ovarian endometrioma – level A	Proportion of patients with endometriosis in whom a transvaginal sonography is performed to diagnose or to exclude an ovarian endometrioma	Numerator: data can be derived from health insurance data (IMA – AIM)



Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
<i>ESHRE 2022:</i> <i>Clinicians are recommended to use imaging (US or MRI) in the diagnostic work-up for endometriosis, but they need to be aware that a negative finding does not exclude endometriosis, particularly superficial peritoneal disease – low level of evidence</i>	<i>ESHRE 2022:</i> <i>Proportion of patients with endometriosis in whom imaging (US or MRI) in the diagnostic work-up for endometriosis is performed</i>	Denominator: no data available on the number of patients with endometriosis <i>Comment:</i> should patients with a suspicion of endometriosis be included too in the denominator?
iv) Assess ureter, bladder and bowel involvement by additional imaging if there is a suspicion based on history or physical examination of deep endometriosis, in preparation for further management – GPP <i>Not (separately) in ESHRE 2022 (included in other recommendation, cf. supra)</i>	Proportion of patients with endometriosis in whom additional imaging is performed to assess ureter, bladder and bowel involvement, if there is a suspicion based on history or physical examination of deep endometriosis	Numerator: data can be derived from health insurance data (IMA – AIM), if ‘additional imaging’ is specified Denominator: no data available on the number of patients with endometriosis, and certainly not on the number of patients with a suspicion of deep endometriosis
Treatment of endometriosis-associated pain		
v) Counsel women with symptoms presumed to be due to endometriosis thoroughly, and empirically treat them with adequate analgesia, combined hormonal contraceptives or progestogens – GPP <i>ESHRE 2022:</i> <i>Women may be offered NSAIDs or other analgesics (either alone or in combination with other treatments) to reduce endometriosis-associated pain – very low level of evidence</i>	A. Proportion of patients with endometriosis who received counselling B. Proportion of patients with endometriosis who received analgesia, combined hormonal contraceptives or progestogens <i>ESHRE 2022:</i> <i>Proportion of patients with endometriosis(-associated pain) who are offered NSAIDs or other analgesics</i>	Numerator A: data cannot be derived from health insurance data Numerator B: data can be derived from farmanet, yet, the purchase of analgesia will be underestimated since a large proportion of NSAIDs and paracetamol are not reimbursed/covered by the health insurance. Also, the aspect ‘adequate’ cannot be measured. Denominator: no data available on the number of patients with endometriosis <i>Comment:</i> should the denominator be restricted to patients with endometriosis-associated pain?
vi) Prescribe hormonal treatment [hormonal contraceptives (Level B), progestagens (Level A), antiprogestagens (Level A) or GnRHagonists (Level A)]	Proportion of patients with endometriosis who received hormonal contraceptives, progestagens, antiprogestagens or GnRHagonists	Numerator: data can be derived from farmanet, yet, the purchase of contraceptives in citizens >25 year old will be underestimated since not reimbursed/covered by the



Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
as one of the options, as it reduces endometriosis-associated pain – level A-B <i>ESHRE 2022:</i> <i>It is recommended to offer women hormone treatment (combined hormonal contraceptives, progestogens, GnRH agonists or GnRH antagonists) as one of the options to reduce endometriosis-associated pain – moderate level of evidence</i>	<i>ESHRE 2022:</i> <i>Proportion of patients with endometriosis(-associated pain) who are offered hormone treatment (combined hormonal contraceptives, progestogens, GnRH agonists or GnRH antagonists)</i>	health insurance (except in citizens eligible for increased reimbursement). Denominator: no data available on the number of patients with endometriosis <i>Comment:</i> should the denominator be restricted to patients with endometriosis-associated pain?
vii) Take patient preferences, side effects, efficacy, costs and availability into consideration when choosing hormonal treatment for endometriosis-associated pain - GPP <i>ESHRE 2022:</i> <i>The GDG recommends that clinicians take a shared decision-making approach and take individual preferences, side effects, individual efficacy, costs, and availability into consideration when choosing hormone treatments for endometriosis-associated pain - GPP</i>	/	Not measurable
viii) Prescribe hormonal add-back therapy to coincide with the start of GnRH agonist therapy, to prevent bone loss and hypoestrogenic symptoms during treatment – level A <i>ESHRE 2022:</i> <i>Clinicians should consider prescribing combined hormonal add-back therapy alongside GnRH agonist therapy to prevent bone loss and hypoestrogenic symptoms - moderate level of evidence</i>	Proportion of patients with endometriosis taking GnRH agonist therapy who also received hormonal add-back therapy <i>ESHRE 2022:</i> <i>idem</i>	Numerator: data can be derived from farmanet, yet, the purchase of contraceptives in citizens >25 year old will be underestimated since not reimbursed/covered by the health insurance (except in citizens eligible for increased reimbursement). Denominator: no data available on the number of patients with endometriosis; selection of women taking GnRH agonist therapy can be derived from health insurance data (IMA – AIM)



Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
ix) Surgically treat endometriosis when identified at laparoscopy, i.e. ‘see and treat’, as this is effective for reducing endometriosis-associated pain – level A <i>ESHRE 2022:</i> /		
x) Refer women with suspected or diagnosed deep endometriosis to a centre of expertise that offers all available treatments in a multidisciplinary context – GPP <i>ESHRE 2022:</i> <i>The GDG recommends that women with deep endometriosis are referred to a centre of expertise - GPP</i>	Proportion of patients with suspected or diagnosed deep endometriosis, who are referred to a centre of expertise that offers all available treatments in a multidisciplinary context <i>ESHRE 2022:</i> <i>idem</i>	Numerator: based on hospital discharge data (TCT-data, see Box 5) patients who were diagnosed and treated in a different hospital (campus) can be identified, but based on these data patients being referred by the diagnostic team/hospital cannot be distinguished from patients who take that initiative themselves Denominator: no data available on the number of patients with suspected or diagnosed deep endometriosis
Treatment of endometriosis-associated infertility		
xi) Perform operative laparoscopy (excision or ablation of the endometriosis lesions) including adhesiolysis, rather than performing diagnostic laparoscopy only in infertile women with AFS/ASRM stage I/II endometriosis, to increase ongoing pregnancy rates – level A <i>ESHRE 2022:</i> <i>Operative laparoscopy could be offered as a treatment option for endometriosis-associated infertility in rASRM stage I/II endometriosis as it improves the rate of ongoing pregnancy – low level of evidence</i>	Proportion of infertile patients with AFS/ASRM stage I/II endometriosis, who receive operative laparoscopy (excision or ablation of the endometriosis lesions) including adhesiolysis, and not diagnostic laparoscopy only <i>ESHRE 2022:</i> <i>Proportion of infertile patients with rASRM stage I/II endometriosis, who receive operative laparoscopy</i>	Numerator: distinction between operative and diagnostic laparoscopy can be made based on hospital discharge data based on ICD-10-BE procedure codes (MZG – RHM or TCT-data) Denominator: no data available on the number of infertile patients with AFS/ASRM (rASRM) stage I/II endometriosis
xii) Perform excision of the endometrioma capsule, instead of drainage and electro coagulation of the endometrioma wall in infertile women with ovarian	Proportion of infertile patients with ovarian endometrioma undergoing surgery, in whom excision of the endometrioma capsule, instead of drainage and	Numerator: the type of tissues excised <i>and other procedures performed during surgery</i> cannot be



Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
endometrioma undergoing surgery, to increase spontaneous pregnancy rates – level A <i>ESHRE 2022:</i> <i>When performing surgery in women with ovarian endometrioma, clinicians should perform cystectomy instead of drainage and coagulation, as cystectomy reduces recurrence of endometrioma and endometriosis-associated pain – low level of evidence</i>	electro coagulation of the endometrioma wall is performed <i>ESHRE 2022:</i> <i>Proportion of patients with ovarian endometrioma undergoing surgery, in whom cystectomy is performed and not drainage or coagulation</i>	identified based on health insurance nor on hospital discharge data (TCT-data) Denominator: no data available on the number of infertile patients with ovarian endometrioma; the surgical intervention can be identified from health insurance or hospital discharge data (TCT-data); <i>no data available on the number of patients with ovarian endometrioma</i>
xiii) Counsel women with endometrioma regarding the risks of reduced ovarian function after surgery and the possible loss of the ovary. The decision to proceed with surgery should be considered carefully if the woman has had previous ovarian surgery – GPP <i>ESHRE 2022:</i> <i>When performing surgery for ovarian endometrioma, specific caution should be used to minimise ovarian damage – very low level of evidence</i>	/	Not measurable
xiv) Use assisted reproductive technologies for infertility associated with endometriosis, especially if tubal function is compromised or if there is male factor infertility, and/or other treatments have failed – GPP <i>ESHRE 2022:</i> <i>Although the value of intrauterine insemination (IUI) in infertile women with rASRM stage III/IV endometriosis with tubal patency is uncertain, the use of IUI with ovarian stimulation could be considered – very low level of evidence</i>	Proportion of infertile patients with endometriosis, including patients with compromised tubal function and patients whose male partner is affected by infertility, who receive assisted reproductive technologies <i>ESHRE 2022:</i> <i>Proportion of infertile patients with rASRM stage III/IV endometriosis with tubal patency in whom intrauterine insemination is performed</i>	Numerator: the use of assisted reproductive technologies (e.g. <i>intrauterine insemination</i>) can be derived from health insurance data (IMA – AIM) Denominator: no data available on the number of infertile patients with endometriosis, nor on the number of patients with endometriosis and a compromised tubal function, the number of patients with endometriosis and a male factor infertility, or on the number of patients with endometriosis in whom other treatments have failed (only the procedure is recorded, not the result); <i>no data available on the number of infertile patients with rASRM stage III/IV endometriosis</i>



Recommendation* in ESHRE guideline (2014, 2022) – level of evidence	Quality indicator (based on ESHRE 2014, 2022)	Measurability**/comments
Miscellaneous topics		
xv) Continue to treat women with a history of endometriosis after surgical menopause with combined estrogen/progestagen or tibolone, at least up to the age of natural menopause – GPP <i>ESHRE 2022:</i> <i>When a decision is made whether to remove the ovaries, the long-term consequences of early menopause and possible need for hormone replacement therapy should be considered - GPP</i>	Proportion of patients with a history of endometriosis and a surgically induced menopause, who receive combined estrogen/progestagen or tibolone (at least up to the age of natural menopause) <i>ESHRE 2022:</i> <i>Proportion of patients with endometriosis in whom the ovaries were removed, who receive hormone replacement therapy</i>	Numerator: the use of estrogen/progestagen or tibolone can be derived from farmanet; no data on patient-specific age of natural menopause Denominator: no data available on the number of with (a history of) endometriosis; data on the removal of the ovaries (which results in surgically induced menopause) can be derived from health insurance data (IMA – AIM)
xvi) Fully inform and counsel women about any incidental finding of endometriosis – GPP <i>ESHRE 2022:</i> <i>The GDG recommends that clinicians should inform and counsel women about any incidental finding of endometriosis</i>	/	Not measurable
xvii) Inform women with endometriosis, requesting information on their risk of developing cancer that (i) there is no evidence that endometriosis causes cancer, (ii) there is no increase in overall incidence of cancer in women with endometriosis and (iii) some cancers (ovarian cancer and non-Hodgkin's lymphoma) are slightly more common in women with endometriosis - GPP <i>ESHRE 2022:</i> <i>Clinicians should inform women with endometriosis requesting information on their risk of developing cancer that endometriosis is not associated with a significantly higher risk of cancer overall. Although endometriosis is</i>	/	Not measurable

**Recommendation* in ESHRE guideline (2014, 2022)
– level of evidence****Quality indicator (based on ESHRE 2014, 2022)****Measurability**/comments**

associated with a higher risk of ovarian, breast, and thyroid cancers in particular, the increase in absolute risk compared with women in the general population is low – low level of evidence

**: Selection of recommendations based on Schleedoom et al., 2016;²⁵⁶ **: appraisal of the numerator measurability is done irrespective of the denominator measurability; Level A: meta-analysis, systematic review or multiple randomized controlled trials (high quality); Level B: meta-analysis, systematic review or multiple randomized controlled trials (moderate quality); Level C: single randomized controlled trial, large non-randomized trial, case-control or cohort studies (moderate quality); Level D: non-analytic studies, case reports or case series (high or moderate quality); GPP: good practice points, expert opinion; ESHRE, European Society of Human Reproduction and Embryology; GnRH, gonadotropin-releasing hormone; AFS/ASRM, American Fertility Society/American Society for Reproductive Medicine; IUI: intrauterine insemination.*

Box 14 – Proposed outcome set for endometriosis (Duffy et al., 2020)**Outcomes evaluating potential treatments for pain and other symptoms associated with endometriosis:**

- Overall pain
- Improvement in the most troublesome symptom
- Quality of life

Outcomes evaluating potential treatments for infertility associated with endometriosis:

- Viable intrauterine pregnancy confirmed by ultrasound
- Pregnancy loss, including ectopic pregnancy, miscarriage, stillbirth, and termination of pregnancy
- Live birth
- Time to pregnancy leading to live birth
- Gestational age at delivery
- Birthweight
- Neonatal mortality
- Major congenital abnormalities

Outcomes applicable to all trials:

- Adverse events
- Patient satisfaction with treatment

Source: Duffy et al., 2020²⁶⁶