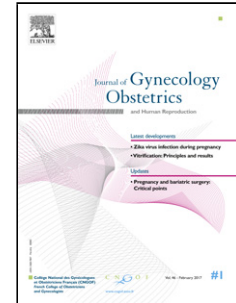


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The definition of Endometriosis Expert Centres*

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Abstract

Endometriosis is a common condition that causes pain and infertility. It can lead to absenteeism and also to multiple surgeries with a consequent risk of impaired fertility, and constitutes a major public health cost. Despite the existence of numerous national and international guidelines, the management of endometriosis remains suboptimal. To address this issue, the French College of Gynaecologists and Obstetricians (CNGOF) and the Society of Gynaecological and Pelvic Surgery (SCGP) convened a committee of experts tasked with defining the criteria for establishing a system of care networks, headed by Expert Centres, covering all of mainland France and its overseas territories. This document sets out the criteria for the designation of Expert Centres. It will serve as a guide for the authorities concerned, to ensure that the means are provided to adequately manage patients with endometriosis.

Keywords: endometriosis, severe endometriosis, expert centres criteria

1- Introduction

Endometriosis is a common female condition, that could affect 10% of women of childbearing age and one-third of infertile women. It is a major public health concern, with substantial costs to the individual and to society. Although gynaecological in origin, it can spread to any abdominal organ (and sometimes beyond), and its presenting symptoms are highly variable. As a result, it is difficult to diagnose and frequently managed inappropriately. Under the circumstances, establishing multidisciplinary Expert Centres in France seems a valid option. To address this, the French College of Gynaecologists and Obstetricians (CNGOF) and the Society of Gynaecological and Pelvic Surgery (SCGP) convened a committee of experts tasked with defining the criteria for establishing a system of care networks, headed by Expert Centres, covering all of mainland France and its overseas territories.

The aim of this document is to propose a national model for Expert Centres in order to improve the management of endometriosis in France (from early diagnosis to the management of severe forms), ideally as part of a national Health Plan.

2- Problems associated with endometriosis in France

i. Difficult to diagnose and to treat

The first issue is that the symptoms of endometriosis (pain, dysmenorrhoea and deep dyspareunia) are trivialised. More advanced disease can be accompanied by gastrointestinal, urinary tract and thoracic disorders which, at least initially, are catamenial. Most of these symptoms are not considered pathological by the general public or indeed by certain health professionals. Next is the issue of delayed diagnosis, due in part to the fact that endometriosis is often poorly understood by general practitioners and even by some of the specialists concerned (gynaecologists, paediatricians, gastroenterologists, urologists, pulmonologists, radiologists, psychiatrists), and to the lack of routine diagnostic tests enabling systematic timely diagnosis. Finally, the management of endometriosis is often sporadic and partial.

ii. Consequences for the woman's health

Delayed diagnosis allows chronic pain to become established, which is both physically and mentally incapacitating and results in repeated medical consultations and sometimes in doctor shopping.

Inappropriate management, due to the absence of a long-term treatment strategy, means that women are often prescribed drugs that may improve symptoms temporarily but at a cost of considerable side effects. Surgical treatment for complex endometriosis, defined as requiring a non-gynaecological surgical procedure, is often suboptimal too and associated with a relative high risk of severe complications. Although no surgeon volume threshold has been clearly defined (a figure of twenty complex surgeries per year has been suggested), it is probable that there is a threshold below which surgical complication rates and the risk of disease recurrence increase.

Infertility: Endometriosis affects close to one-third of infertile women, and women with severe forms of endometriosis often require assisted reproductive techniques and extensive surgery.

Extensive surgery: These operations can cause an alteration in body image, may require an intestinal stoma, and entail considerable morbidity.

iii. Economic impact

The economic impact of endometriosis must be considerable, because it is a chronic disease (although not yet considered as such in France) that generates major health costs unconnected to the initial cause.

3- Background and opportunities

Having lobbied for over 10 years, the French endometriosis patient organisation Endofrance managed to raise awareness among policy makers of the shortcomings in the management of this disease and of the value of creating Expert Centres for endometriosis.

The first proposal for an Expert Centre in the Haute-Normandie region was submitted to the ministry of health in 2013.

Scientific societies then expressed their interest in the issue, including the Society of Gynaecological and Pelvic Surgery (SCGP) in 2014 and the French College of Gynaecologists and Obstetricians (CNGOF) in 2015.

At the first EndoMarch in Paris, in March 2014, the Together against Endometriosis collective (*Ensemble contre l'Endométriose*) handed the Minister for Women's Rights a manifesto titled Endometriosis: Open Your Eyes (*Endométriose: ouvrons les yeux*).

In 2015 and in 2016, a raft of initiatives by civil society groups, politicians and media personalities raised public awareness of this condition.

In March 2016, the proposed Expert Centre in Normandy was approved as a pilot project to evaluate this approach.

A partnership agreement with the group *Info Endométriose* was signed by the Ministry for Education in June 2016 and the Ministry for Family, Children and Women's Rights in March 2017 to enhance information of the female population especially the adolescents.

Between early 2016 and late 2017, at the request of the health minister, the French National Authority for Health (HAS) updated its guideline on the diagnosis and management of endometriosis, in consultation with health professionals and patient organisations and based on current evidence, with the aim of constructing a new model for the management of women with endometriosis.

In 2017, in parallel to drafting the updated practice guideline on endometriosis, the CNGOF, in agreement with the SCGP, convened a committee of experts to consider the question of Expert Centres for endometriosis. The committee concluded that they would be beneficial, and set out the requirements they would need to meet.

4- The objectives of a system of Expert Centres

Improve the diagnosis and management of endometriosis in France, uniting health professionals with expertise in endometriosis from various disciplines. The improvements sought would require Expert Centres to:

- **Train health professionals** through seminars, postgraduate education, conferences, etc.
- **Develop basic and clinical research.**

- **Coordinate health professionals** with particular expertise in endometriosis and harmonise practices through multidisciplinary team (MDT) meetings.
- **Inform the public** through a website and media information campaigns.
- **Facilitate patient access** (spontaneously or through their doctor) to health professionals with the necessary expertise.
- **Determine a tailored long-term treatment strategy** based on the patient's age, disease and her priorities.

Expert Centres will need to be distributed geographically so as to provide coverage for the entire population of France. However, as France's 13 regions vary in their catchment populations and the distances patients would need to travel, it will be necessary to determine the number and location of Expert Centres on a case-by-case basis, and to find solutions for overseas departments and territories.

5- Requirements of a system of Expert Centres

These proposals are based on the Ministry of Health's recommendations aimed at ensuring high-quality tertiary care by setting up referral facilities. Expert Centres will be regional in scope. They will have the following responsibilities:

- Responsibility for organising geographical coverage**
- Responsibility for the full pathway of care and tertiary care**
- Responsibility for communication and education**
- Responsibility for research and evaluation**

6- Organisational structure of Expert Centres

In its geographical area, the Expert Centre system will be organised as a pyramid, with a Reference Centre at the top leading a network of Centres of Expertise below.

The Reference Centre: In practice this will be the first Centre of Expertise and qualitatively will have the capacity to carry out all the responsibilities that fall to the Expert Centre. It is a bridgehead, acting as a hub dealing with a range of stakeholders within its geographical area.

Centres of Expertise participating to the network: They will be located in private or public hospitals that request this designation from the Expert Centre and meet the requirements laid down. In particular, they must have a demonstrated track-record in the management of endometriosis, clinicians who participate regularly in the Expert Centre's MDT meetings, and the facilities required to fulfil some of the responsibilities listed above.

7- Responsibilities of Expert Centres

a) **Responsibility for organising geographical coverage:** this role is performed by the Expert Centre, which compiles a directory of its "expert" members and its corresponding members, liaises with users and government bodies, and plans informational and communication activities. It circulates procedures, protocols and guidelines and develops a system for collecting epidemiological data. It organises an MDT meeting at least once a month, attended by the regional "experts". These experts are organised into "colleges" with different and complementary specialties in order to guarantee representation of these disciplines at each meeting. Each MDT meeting must have a quorum composed of at least one gynaecologist, one endometriosis imaging specialist, one specialist in assisted reproductive techniques, and one general surgeon.

b) **Responsibility for the full pathway of care and tertiary care:** the Expert Centre shall have all the available diagnostic and therapeutic resources required for managing endometriosis.

c) **Responsibility for communication and education:**

Communication: this refers to communication between doctors by forwarding information about each patient (standard MDT meeting forms and letters between experts and general practitioners), as well as communicating with patients via a dedicated secretarial office and by engaging with patient organisations.

Educational responsibilities: the Expert Centre shall deliver, promote and participate in university and postgraduate education and training for all professions involved in the management of endometriosis and shall help promote best practice.

d) **Responsibility for research and evaluation:** the Expert Centre shall run a prospective database at least for patients undergoing surgery for complex

endometriosis, operate clinical audit activities (morbidity and mortality conferences, publications, etc.), collect annual caseload data, and participate in basic or clinical research.

8- Funding

Financing must be long-term in order for the Expert Centre to carry out all of its responsibilities. Below is a non-exhaustive list of the types of financing sought.

a) **Financial needs:**

Expert Centre operating costs: Two types of operating cost are needed: medical and non-medical staff costs (one full-time equivalent - FTE- hospital consultant and at least one FTE secretary), and running costs, such as web hosting, webmaster costs, and funding for MDT postgraduate teaching and conferences.

Research expenditure: including running costs for clinical research associates and funding for PhD or Masters students (annual or ad hoc stipends).

- b) **Public sector funding:** which could be structured as a one-off initial investment with renewable operating costs.
- c) **Private-sector funding:** a financial contribution from the pharmaceutical and medical equipment industry towards research projects and training.

9- Conclusion

Given the prevalence of endometriosis, its severity and impact on patients' daily lives, and the health costs it generates, this disease deserves specific high-quality management. The creation of Expert Centres will optimise this management.

There is an urgent need for the role of these centres to be officially recognised through certification by the French health authorities, and for them to be allocated sufficient human and financial resources, ideally as part of a national Health Plan for Endometriosis.