



# Acknowledgements

The RCN would like to thank the project team who originally developed these standards in 2018. This edition was updated in 2021 by:

Debra Holloway FRCN, Nurse Consultant Gynaecology, Guy's and St Thomas' NHS Foundation Trust and RCN Women's Health Forum Committee

Carmel Bagness, Professional Lead Women's Health and Midwifery, RCN

Wendy Norton FRCN, Associate Professor/Reader, Faculty of Health and Life Sciences, The Leicester School of Nursing and Midwifery, De Montfort University, Leicester

Gilly Macdonald, BSGE Endometriosis Nurse Representative, British Society for Gynaecological Endoscopy



© 2021 Royal College of Nursing. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers. This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

# Contents

1 Introduction 4

---

“ # ê CE % ê% å , \$ZèK , R R —

---

” ” ê K , êÿZ ê ß % ß%Ã ` K R ê ê ß Ó RCE ø%  
ê % å , \$ZèK , R R ~

---

3.1 Special ist commissioning for managing advanced endometriosis 8

---

3.2 Special ist service centre aims 10

---

3.3 CNS responsibilities 11

---

• \_ CE % ê % å , \$ZèK , R R ê ß Ó R% å% , w ê å ê ’ “

---

4.1 Clinical practice skills 14

---

4.2 Leadership skills 15

---

4.3

---





...ê ß, % Æ % Æ ß ÿ Æ % Æ Z , % Æ Z Æ Æ Æ Æ Æ, è% “ ‘ ’™ ã  
the RCN Women’s Health Forum, in collaboration with Endometriosis UK  
and the BSGE, devised a skills and knowledge framework that would  
inform and enhance local practice and establish a base line standard  
across the UK.

# è Æ % Z% è ð K è Æ Æ Æ Z Æ Æ Æ Z Æ Æ % Æ , \$ è Z K ß, R% R Æ Æ % ` K R è  
specialist role was intended to enhance career opportunities for  
nurses seeking to develop their own skills to become a CNS. It is still  
envisaged that masters level academic learning should complement the  
development of this role.

” è H K , Æ Æ Æ \$ , H Z Æ Æ Z è Æ % Z% è | H è ß Z Æ Z w , % Æ H K , v Æ è  
a clear direction for commissioners and managers when creating  
roles to support best practice in local service delivery. The clear  
Æ è Æ % Z ÿ , % Æ Æ v Æ Æ Æ , \$ H , % è % R Z R Æ % % Z % R ` Z Æ Z  
the responsibilities of the endometriosis CNS is clearly understood  
but ultimately enable specialist centres to elevate the quality of care  
delivered for women.

R H Æ K Z R , K Z Æ è H K , Æ Æ Æ \$ Æ è % Z Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ Æ  
yet effective information sheet that would enable nurses, and other  
health care workers coming into contact with women who may have  
endometriosis, to recognise the disease symptoms and support initial  
management of this condition.

This fact sheet (see Æ H H è % Æ | ’) pro <020EpFF0020>>>05012C>8.5 <0160>



# 3 The role of the clinical nurse specialist (CNS) in endometriosis

The role of the CNS in managing and supporting women with

- lead and develop services
- ensure these services are linked with primary care
- support a better understanding of this condition among all nurses coming in contact with women

Following the commissioning of complex gynaecology services, the care of women with complex endometriosis has been highlighted. Whilst minor and moderate cases of endometriosis can be managed in all gynaecology departments (with a specialist nurse who is interested in endometriosis),



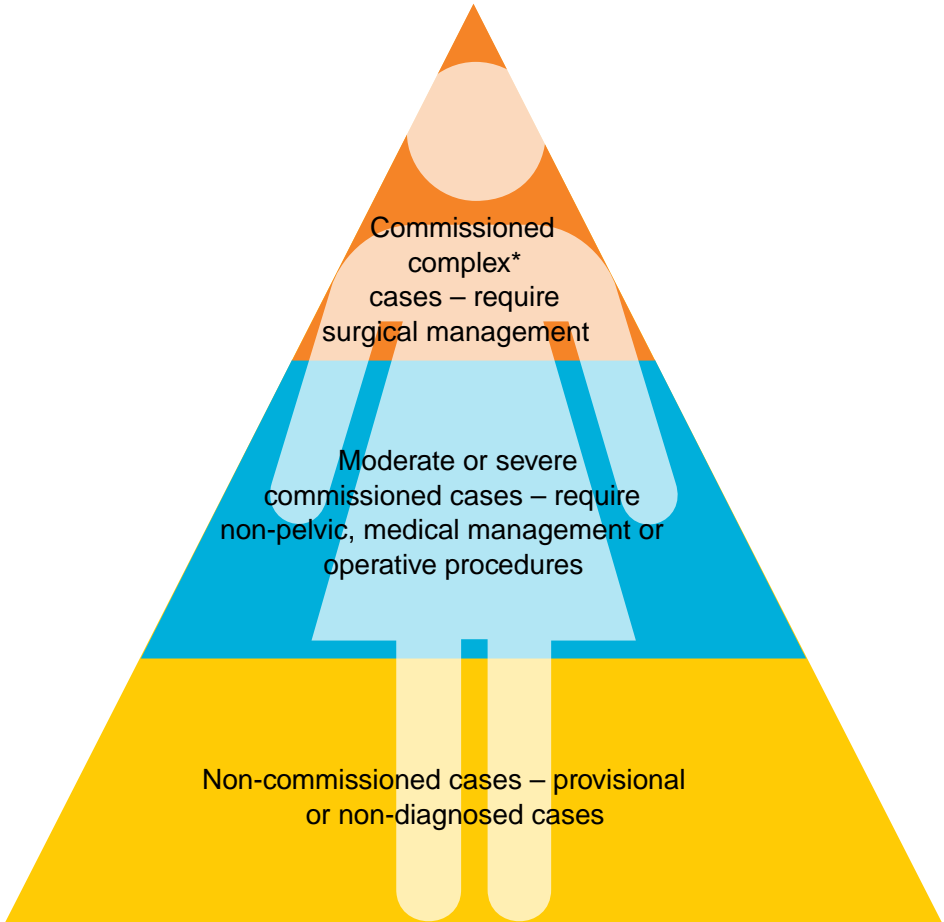
### 3.1 Specialist commissioning for managing advanced endometriosis

For the purposes of specialist commissioning services, severe





Figure 1 – Scale of need for women with a provisional and actual diagnosis of endometriosis



\*Complex as defined by specialist commissioners (NHS England, 2013)

### 3.2 Specialist service centre aims

The primary aim of endometriosis centres is to provide woman-centered specialist care that helps improve the quality of life for women with severe endometriosis.

As these centres expand and develop, however, the CNS workload is set to evolve. At the present time, commissioning documents refer only to women with severe disease symptoms. In the future (and in light of the “‘’ ~ \_ F ( ` ` á ê Z % é R é K v \$ A é P é | Z é % á z é, z Á ê % z Á, ß ß, ` % Z the large number of women with endometriosis who do not require operations and receive non-surgical management and support.

The delivery of an excellent woman-centred service to women with endometriosis is achieved by:

- ß ê Á k é P E % % é | A P % Á % Z % é | Z é % y Z é R é Á R é
- providing appropriate counselling and psychological support
- providing a nurse specialist to act as the interface between a woman and the specialist teams required to complete her care
- % á v á ` Á ß Á K é Á R, é á v, \$ Á % R R H é ß R é \$ H Z ß \$ \$ H é | Z } Ó b

### 3.3 Clinical nurse specialist 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
  -

## 4 Clinical nurse specialist in endometriosis role: skills and knowledge



## Figure 2 Overview of clinical nurse specialist skills

## 4.1 Clinical practice skills

-

## 4.2 Leadership skills

- To be the woman's advocate in relation to surgery and treatment.
- To have the ability to work independently, as well as part of the multidisciplinary team, and to be organised.
- To be an autonomous practitioner while also working across and within multiple specialty teams.
- To be aware of the value and costing of the service by looking at the impact of the CNS on service users; for example, by user satisfaction ratings, number of consultations, number of women seen and number contacted, audit of appointment cancellations and audit of pathway in conjunction with management teams.

## 4.3 Data collection and management

- To contribute towards the collection and analysis of data, including quality of life surveys, own centre audit and research data.
- Service evaluation, including women's views on the service and individual women in relation to quality of life and symptoms.
- Informs research and uses research in practice.
- The assessment of individual women at each step of the pathway and the use of this data to inform the medical team/or consultant of a woman's progress, or if sooner follow-up is needed.
- IT skills should incorporate database, protocols, literature searching, audit, questions, research, word processing and spreadsheets (such as Microsoft Word and Excel packages).

## 4.4 Service provision/pathway management/ co-ordination

- Team work –this includes working with the multidisciplinary team to co-ordinate the care in outpatients, during surgical interventions and with other specialities.
- To ensure a streamlined service in all areas of care.
- To be the central point of contact for women.
- The co-ordination of services, for example medics, databases, outpatient appointments and surgery.
- Liaison with the colorectal team if dealing with a woman who has a stoma.
- The design and monitoring of care pathways.
- To be aware of women who have had a hysterectomy and are still experiencing problems –necessitating referral or liaison with the pelvic pain clinic or menopause clinic.
- Provide emotional support to women.

## 4.5 Education and training delivery

- To provide education to health care professionals, women and their partners in relation to endometriosis.
- To educate nurses and medical staff within gynaecology and, if needed, to develop programmes with primary care.
- Work with practice nurses to identify women who may have the condition.





Ä.Æ 0 ® ÿµH2P :P: /2 Üöµ ®µhµö /ÿµ H

•

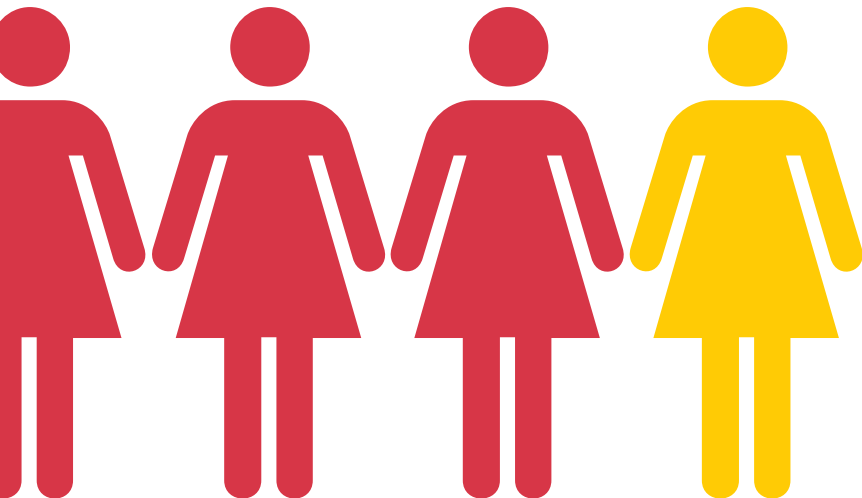


# 5 Conclusion

The clinical nurse specialist is a key post within the endometriosis team for women requiring care and support. The position represents an exciting opportunity for nurses to develop into a leadership role in a collaborative environment. It is recognised as a strategic leadership opportunity for nurses who specialise in an important aspect of woman's health care.

Research published by Norton et al., (2020) on The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy registered centres, and how the role aligned to the RCN A UK survey of practice. Nursing open This research has enhanced continuing collaboration by the RCN, BSGE and Endometriosis UK to further develop support for this role, and aims to ensure all CNSs can work to their full potential for quality effective care for all women who may have or be suspected of having endometriosis.

commissions to have stipulated that a service should have a nurse within the team and this development should be welcomed and celebrated as an attractive career opportunity for nurses.





# Appendix 1: Endometriosis factsheet

## What is endometriosis?

Do you see female patients? Do they have painful periods? Pain pre or post their periods? Painful sex? Do they suffer chronic pelvic pain, which may be intermittent or constant? Do they have pain when passing urine or with bowel movements? Is it painful to place a speculum for a smear test?

## Have you considered endometriosis?

One in 10 women have endometriosis and it takes an average of eight years for women to get diagnosed. Endometriosis can often be confused with or misdiagnosed as IBS (irritable bowel syndrome). It is important that women receive a early diagnosis, or working diagnosis,



2 ýµ 1PÞşò ĨŠşH: Š ® ŪĐP2µ: Š! PH µ ® ýµH2P :

<ÃßZR Ã%â œ `KêR û ýK,\$ (%â,\$êZK ,R R šV  
[endometriosis-uk.org](http://endometriosis-uk.org)

- **One in 10** women of reproductive age (between puberty and \$ê%,HÃ`Rêô % Z ê šV R`ÿÿêK ýK,\$ ê%â,\$êZK ,R R â
- **10%** ,ÿ w,\$ê% w,K âw âê Ãvê ê%â,\$êZK ,R R ú Z ÃZ R  
**190 million worldwide** .
- The prevalence of endometriosis in women with infertility is as  
ÃR –‘F â
- Endometriosis is the second most common (prevalence 0.84-2.048 per 1000 women aged 15-44 years) cause of infertility (10-15% of women with infertility)

## à Ø ÿ Š o ! μ Š Ĩ ĩ μ § H μ ® /

Women of any age can be affected by endometriosis but it is rare for the  
β , % á Z , % Z , \$ Ā % ÿ ê R Z Þ ê ÿ , K ê Ā K Ā R ê K Œ K R Z H ê K

Teenagers who suffer with painful periods, experience fainting or collapse when having a period, or who miss school because of their period problems should be considered as possibly suffering from the condition.

### What are the symptoms?

Symptoms may vary from woman to woman and some women may experience no symptoms at all (or may not recognise their symptoms as abnormal).

Typical endometriosis symptoms include:

- painful periods
-

## !Š2μ ŷŠ ŠĐμŷμ H ɓ /2ɓŷŠ2o §Š2μ

Suspected endometriosis may be managed in primary care but consider referral to gynaecology or a specialist endometriosis centre if there is any suspicion or uncertainty over the cause of pain or if women are presenting with fertility issues. Women with suspected deep

- if the woman has fertility problems
- if surgical and medical management of endometriosis is required
- if complex/severe endometriosis is suspected—for example, endometriomas or where endometriosis is affecting the bowel (NICE 2018 quality standard)
- if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated (NICE guidelines 2017 and Quality Standard 2018).

Please note, a six-month timescale can be used to decide whether initial hormonal treatment is effective however a referral should be made before six months if it becomes clear that treatment is not effective.

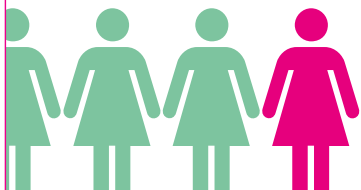
### Care in secondary care and endometriosis centres

Women with endometriosis often need referral to secondary care for the diagnosis and treatment of the condition.

The investigations offered include ultrasound scan, although a negative scan or MRI does not rule out endometriosis, therefore the gold standard for diagnosis is laparoscopy with biopsy. Laparoscopy can be diagnostic but more often this is combined with operative surgical procedures to remove the endometriosis. Investigations offered should include a

Cases of severe endometriosis (or suspected severe endometriosis) should be sent to a specialist BSGE (British Society for Gynaecology Endoscopy) accredited endometriosis centre where women can access specialist gynaecologists and a clinical nurse specialist (CNS) who work in conjunction with general surgeons and urologists. These specialist centres also liaise with pain management teams and have links with a local fertility team.

A full list of accredited specialist endometriosis centres in the UK can be found online at the BSGE website at: [bsge.org.uk](https://www.bsg.org.uk)









## Endometriosis

Please tear off this section and give it to women who you feel should seek a referral.



