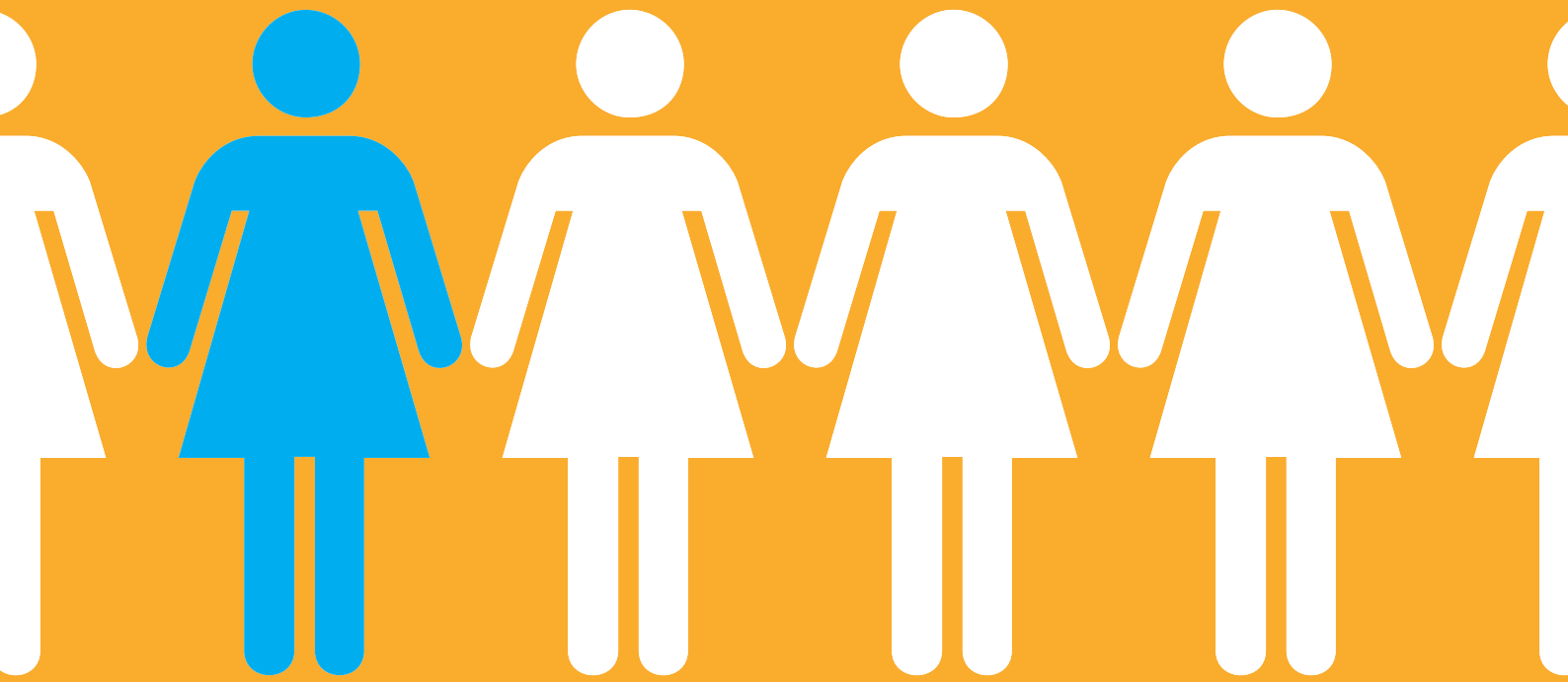
Royal College of Nursing

Clinical Nurse Specialist in Endometriosis

CLINICAL PROFESSIONAL RESOURCE



Acknowledgements

The RCN would like to thank the project team who originally developed these standards in 2018. This third edition was updated in 2024 by:

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Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

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Notes

It is recognised that care may be provided by registered nurses and midwives, health care support workers, assistant practitioners, nursing associates, student nurses and midwives, and trainee nursing associates. For ease of reading, the generic terms 'nurse', 'nursing' and 'nurses' are used throughout this document, unless specified.

The RCN recognises and embraces our gender diverse society and encourages this guideline to be used by and/or applied to people who identify as non-binary, transgender, or gender fluid.

The RCN also recognises that not all those born female or male will identify with the same gender nouns, but for ease of reading we use the term woman/man/men and where appropriate, acknowledge non-binary terms.

1 Introduction

Endometriosis is a life challenging disorder that affects over 1.5 million women in the UK – 1 in 10 women and those assigned female at birth from puberty to menopause although the impact may be felt for life. It is a complex illness that is often not quickly diagnosed when women first present with symptoms.

Evidence suggests that care can be delayed due to a lack of awareness and understanding of the disease amongst health care workers, which leads to a lengthy diagnosis – it can take on average eight years for women to receive a full diagnosis and access the best treatment for their condition.

Endometriosis is often misdiagnosed as irritable bowel syndrome, which can have devastating effects on the physical and psychological wellbeing of the women who have to live with this debilitating disease.

As a commissioned service within complex specialist care there are dedicated specialist centres which have been accredited by the British Society for Gynaecological Endoscopy (BSGE). As part of that commissioning review (NHSE, 2018), it was confirmed that women attending these centres would benefit from improved quality of care by having direct access to an endometriosis clinical nurse specialist (CNS) and BSGE accreditation of specialist centres is dependant on having an endometriosis nurse specialist in place. This role has been further recognised by the NICE guidelines (NICE, 2024), which expanded the role of the nurse supporting women with endometriosis or suspected endometriosis. This will impact the nurses who were originally employed to support complex cases.

Recognising the lack of a national standard to define this role, 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.

Defining the breadth and depth of the endometriosis clinical nurse 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.

The project team hoped that defining the expectations would provide a clear direction for commissioners and managers when creating roles to support best practice in local service delivery. The clear definition of individual role components should not only ensure that the responsibilities of the endometriosis CNS is clearly understood but ultimately enable specialist centres to elevate the quality of care delivered for women.

As part of this work, the project team identified the need for a simple, yet effective guide 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.

What is Endometriosis? (publication code: 011 851, available at: **rcn.org.uk/publications**) provides guidance on how to recognise symptoms, sets out pathways of care and signposts useful online resources. It is hoped this resource will prove helpful to those nurses and other health care professionals who do not work directly within the field of women's health and will enable greater awareness of the disease.

2 Defining endometriosis

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction (NHS, 2022). While some women with endometriosis experience painful symptoms and/or infertility, others have no symptoms at all (or may not recognise their symptoms as abnormal). The exact prevalence of endometriosis is unknown however, WHO (March 2023) states Endometriosis affects roughly 10% (190 million) of reproductive age women and girls globally.

Women of any age can have endometriosis however it is rare before the menarche (first menstrual cycle). Teenagers with painful periods, or who faint, collapse or miss school due to their menstrual periods may be demonstrating symptoms that indicate a possible diagnosis of endometriosis.

Some quick facts and figures about endometriosis

- 1 in 10 women and those assigned female at birth of reproductive age (between puberty and menopause) in the UK suffer from endometriosis.
- 10% of women worldwide have endometriosis – that's 190 million worldwide.
- The prevalence of endometriosis in women with infertility is as high as 50%.
- Endometriosis is the second most common gynaecological condition (after fibroids) in the UK.
- Endometriosis health care costs are comparable to other common diseases such as type 2 diabetes, rheumatoid arthritis, and Crohn's disease.
- On average it takes over 8 years from the onset of symptoms to get a diagnosis.
- Endometriosis costs the UK economy £8.2bn a year in treatment, loss of education, work and health care costs.
- The cause of endometriosis is unknown and there is no definite cure, but many different treatment options.

Information provided by Endometriosis UK **endometriosis-uk.org** and European Society of Human Reproduction and Embryology **eshre.eu** (ESHRE, 2022)

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

The role of the CNS in managing and supporting women with endometriosis has been defined to take account of the need to:

- 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), this service specification concerns only severe endometriosis, which has an annual incidence of around 5,000 new cases in the UK per year (NHS England, 2013). However, the RCN supports the need for all women with endometriosis to have access to specialist services to ensure the highest quality care which has been recognised in the NICE guidelines (NICE, 2024). However, this may be difficult to achieve in practice as centres tend to work to hours needed for each complex patient rather than focusing on the needs of individual women, regardless of their situation.

This document builds on this requirement and describes what a CNS might do, and encompasses the care of all women with endometriosis.

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.

3.1 Specialist commissioning for managing advanced endometriosis

For the purposes of specialist commissioning services, severe endometriosis is defined as either deeply infiltrating endometriosis or recto-vaginal endometriosis.

Deeply infiltrating endometriosis exists where the disease invades at least 5mm below the tissue surface and can occur in a variety of sites; this includes the bladder, pelvic sidewalls, ovaries, pelvic brim, bowel surface and diaphragm.

Recto-vaginal endometriosis is endometriosis which involves the recto-vaginal septum area (recto-vaginal septum; vagina; uterosacral ligaments; rectum). There are many classification systems for endometriosis but none are universally accepted.

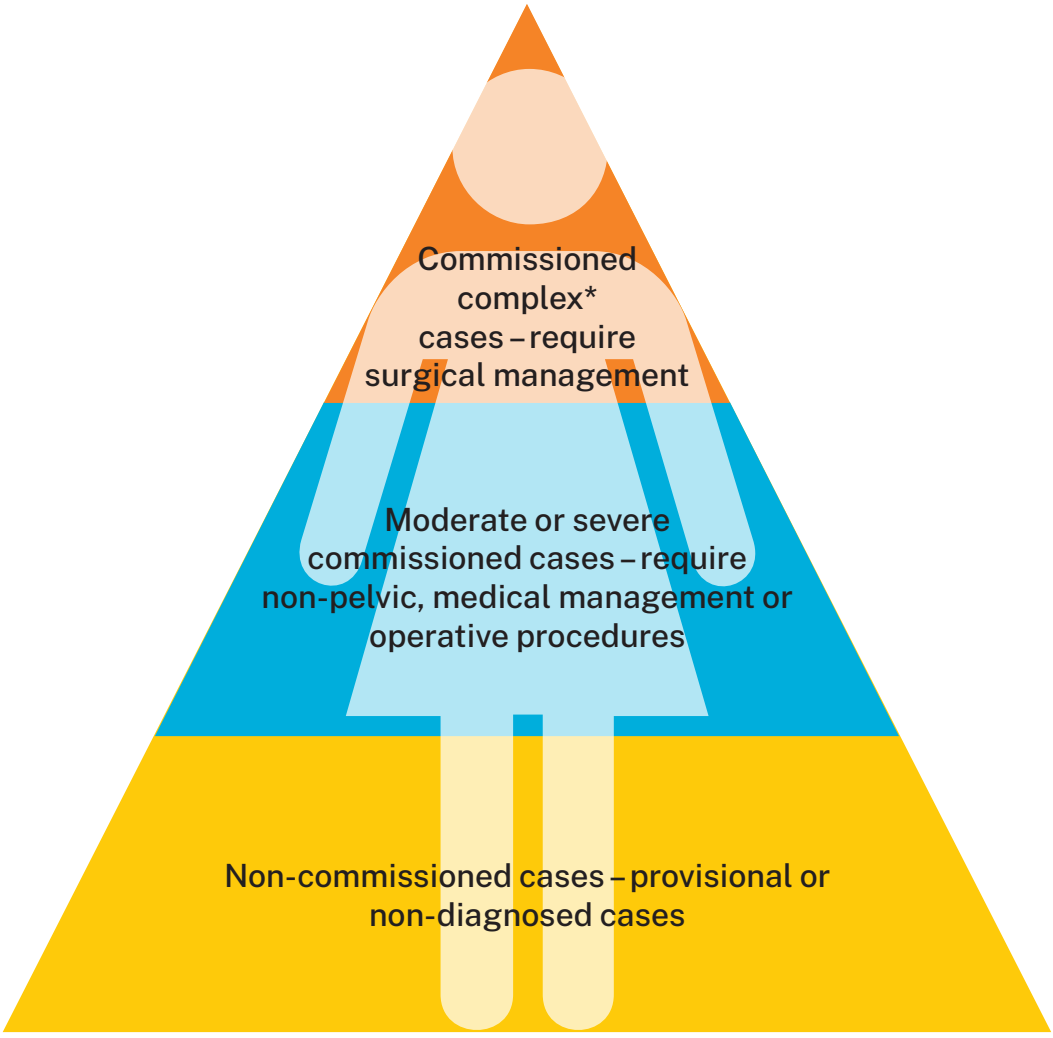
Removing the endometriosis involves complex surgery and national BSGE criteria (see bsge.org.uk) exist which set out the standards of service and workload required to undertake surgical excision of severe endometriosis.

This has driven the establishment of centres where such work can be undertaken by specialist multidisciplinary teams. Within the commissioning documents reference is made to an endometriosis CNS whose role is to liaise directly with women using the specialist service and provide women with support in the management of the condition.

The RCN supports NICE guidance (2024) that all women with suspected or confirmed endometriosis should have access to a gynaecology specialist nurse with expertise in endometriosis/CNS Endometrosis. At present it is more likely that only women at the more complex end of the spectrum of care will have access to these services (see figure 1).

The majority of the role of the CNS endometriosis will focus on women who do not necessarily fall into the specialist category. The majority of women who need support with their symptoms are those who do not fit into the severe category for surgery and those who have endometriosis outside of the pelvis; however these are women on medical therapy and will all need support from the CNS (NICE, 2024).

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



*Complex as defined by specialist commissioners (NHS England, 2024)

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 2017 NICE guideline) the service may be extended to take into account 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:

- clearly defining and explaining the extent of the disease
- 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
- individualising care based on a woman's specific symptom complexity and preferences
- taking account of the woman's fertility needs
- providing high quality treatment and care to relieve the symptoms of endometriosis
- assessing quality of life before, during and after treatment.

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 (in some centres this may include urology and thoracix team as well)
- 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:
  - at six months the endometriosis nurse will review the woman and obtain a completed quality of life questionnaire
  - the same questionnaire will be completed at 12 and 24 months post-surgery and mechanisms for non-face to face consultations (telephone or website submission) need to be in place.

4 Clinical nurse specialist in endometriosis role: skills and knowledge

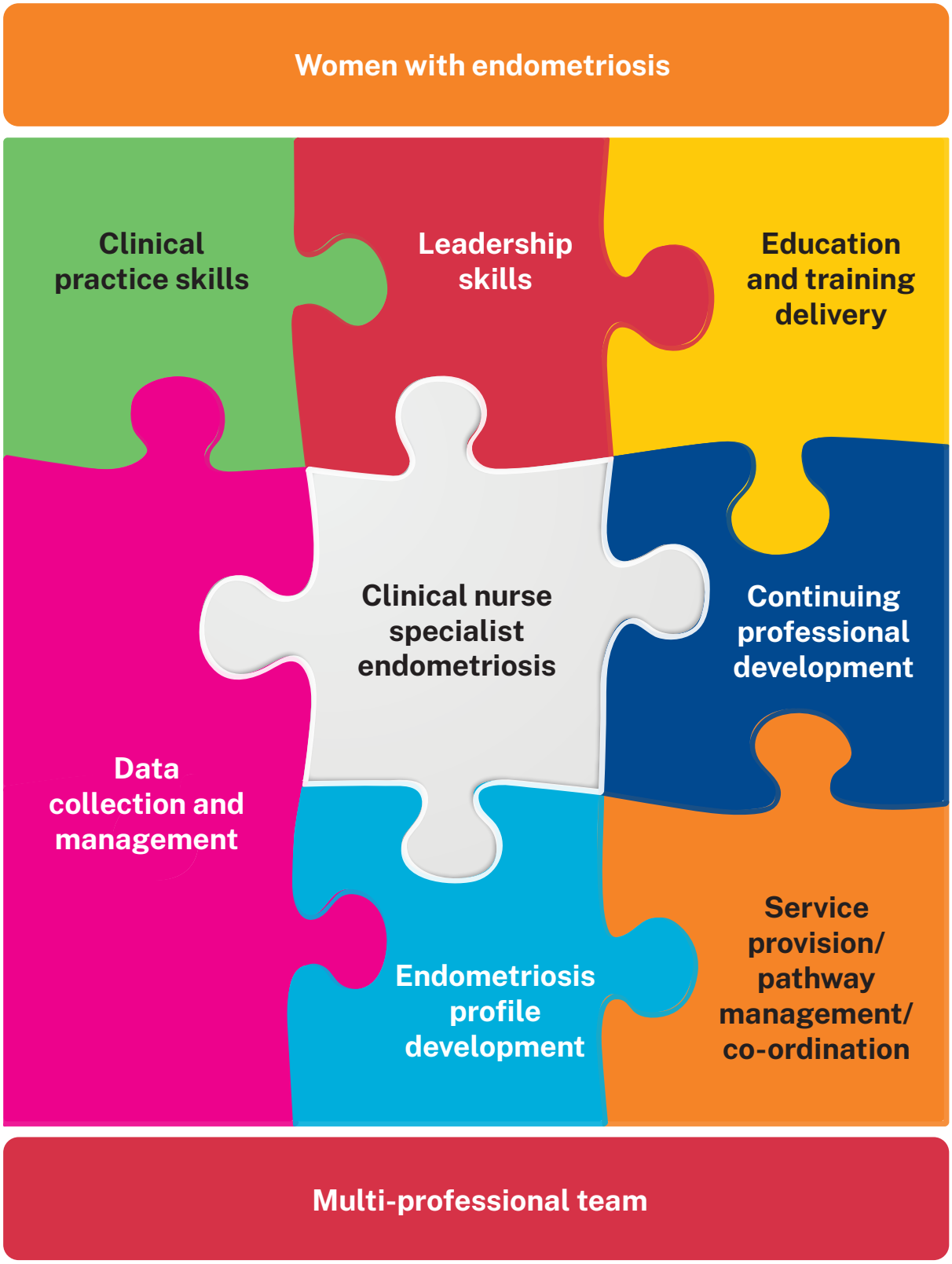
The role of the CNS endometriosis is complex and will demand a range of practice skills, alongside management and leadership insightfulness.

This senior role will require the nurse to be able to:

- be clinically competent and confident in their own practice abilities
- be an inspiration and source of knowledge for others
- use audit tools
- enhance their own education
- consider the need for research to further enhance practice.

It is recognised that this is a developing role and that not all nurses will come with the full skills set required to fulfil all components outlined below.

Figure 2 Overview of clinical nurse specialist skills



4.1 Clinical practice skills

- To have an expert knowledge of the condition, all treatment options (including associated side effects; complementary therapies) and be able to signpost if needed.
- Be able to communicate at all levels, to women, staff, primary and secondary care, written, verbal and phone, including good documentation.
- Be able to undertake consultations independently, which include assessment, history, physical and psychological assessment, for example, pelvic assessment. See also the RCN's 2023 publication *Genital Examination in Women: a Resource for Skills Development and Assessment*, which is available for download at: **rcn.org.uk/publications** (publication code: 007 961) for further information on pelvic assessment.
- To be competent in the use of ordering and interpreting diagnostic tools – scanning, bloods, MRI (magnetic resonance imaging), and laparoscopy in conjunction with the multidisciplinary team.
- To undertake ultrasound or to be able to order and interrupt results.
- To work with women who are inpatients, giving pre- and post-operative care and advice, co-ordination of any appointments on discharge, hormone replacement therapy (HRT) advice, follow-up phone calls.
- To hold own nurse-led clinics, both face to face and as a telephone service.
- To be a non-medical prescriber or work within patient group directives (PGDs) and have knowledge of drug regimes and side effects, including complementary therapies.
- To be able to undertake consent and give operative planning advice.
- To undertake counselling or be able to refer to the appropriate services.
- Undertake referrals – pain, fertility, investigations, psycho-sexual care/counselling, bladder and bowel care, counselling, menopause, mental health, and cognitive behavioural therapy (CBT).
- Advise on complementary therapies.

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 develop educational material for women or be able to find them.
- 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.

4.6 Endometriosis profile development

- To raise awareness among women in clinic and within primary care and to work with support groups to highlight the condition and provide support to women after a diagnosis.
- Create and strengthen links with support groups.
- Understand the local and political landscape and providers and to actively find links in primary and secondary care.
- To provoke interest and engage with others about endometriosis.
- To conduct audits and consider opportunities for research to enhance practice.

4.7 Continuing professional development and levels of practice

- The role of the CNS is complex, and the expectation is that nurses working in this role will be at an advanced level of practice, or working towards it. Consequently CPD needs to reflect this progressive role.
- The education needed for the role is at masters level, with evidence of masters level thinking and problem solving.
- This could include for example advanced clinical skills, advanced physical assessment skills, independent prescribing, skills to present information well, endometriosis module, evidence-based practice, counselling, scanning, leadership, sexual health and contraception.
- Manage effective support for self – a supervision, mentorship, buddying, utilising other clinical nurse specialists and the BSGE network.
- There is an expectation that a nurse within this role is given the opportunity to attend and maintain skills on an annual basis at appropriate national meetings and this can be reflected in revalidation evidence.
- It is recommended that the endometriosis CNS becomes a member of the BSGE to share high quality practice and to have access to expert education and support.
- In 2024, the RCN published *The levels of nursing*, available at: **rcn.org.uk/Professional-Development/Levels-of-nursing**. It is recognised that clinical nurse specialists may work at enhanced or advanced level of practice, dependent on education and expertise, and experience in this specialist field of practice.
- See also: RCN *Advanced level nursing*. **rcn.org.uk/Professional-Development/Levels-of-nursing/Advanced** and the International Confederation for Nurses Guidelines on Advanced Practice Nursing 2020. **icn.ch/system/files/documents/2020-04/ICN_APN%20Report_EN_WEB.pdf**
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5 Conclusion

The clinical nurse specialist is an advanced level 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 Skills and Knowledge, identified areas requiring further development: A UK survey of practice. *Nursing Open*, 7(6), pp.1852-1860 **ncbi.nlm.nih.gov/pmc/articles/PMC7544879**. 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.

This role represents one of the first health service provision 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.

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Useful resources

Endometriosis UK **endometriosis-uk.org**

The British Society for Gynaecological Endoscopy **bsge.org.uk**

European Society of Human Reproduction and Embryology **eshre.eu**
(ESHRE guidelines available at: **eshre.eu**)

Royal College of Obstetricians and Gynaecologists **rcog.org.uk**

The World Endometriosis Society **endometriosis.ca**

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This updated guidance defines the role of the endometriosis clinical nurse specialist (CNS) to enhance career opportunities, inform and enhance local practice, and establish a base line standard across the UK. There is also a *What is Endometriosis?* publication available (011 851).

Publication date: November 2024 Review date: November 2027

The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact **publications.feedback@rcn.org.uk**

Evaluation

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Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333
www.rcn.org.uk

November 2024
Review date: November 2027
Publication code: 011 850

Royal College of Nursing