

## **Submission of Evidence by RCN to APPG Woman's Health on: Informed Choice Inquiry (Endometriosis)**

In February 2017, the RCN joined with a number of key stakeholders in submitting evidence on key issues around Informed Choice and access to care for women suffering from Endometriosis and from Fibroids, the responses, provided via an electronic survey are outlined below.

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The RCN subsequently supported the publication of the report from the ALL-PARTY PARLIAMENTARY GROUP ON WOMEN'S HEALTH APPG called Informed Choice? Giving women control of their healthcare which outlined key recommendations:-

### *Recommendations*

Improve patient experience by:

- 1 Patient information leaflets (endorsed by the RCOG, BSGE, RCGP, RCN and RCR/BSIR and created in conjunction with specialist patient groups) to be used in GP practices, gynaecology clinics and for the general public in a generic format:
  - These should cover information on the condition and information on all treatment options – from hormonal contraception and pharmaceutical solutions, minimally invasive surgery and major surgical intervention.
  - Information should be available for patients and also for families. Information resources should be available, including in multiple languages, audio-visual materials and online website, blogs and testimonies.
- 2 Public awareness on gynaecological concerns focusing on what is normal menstrual health and pelvic pain and what is not.
- 3 Treat all patients with dignity and respect and empower women to make a choice by giving them all the information and access to the specialist services they need.

Improve awareness by:

- 4 Multi professional training and education opportunities to be supported by RCN, RCGP and RCOG – which have CPD points on endometriosis and fibroids.
- 5 PSRE education and SRE to include menstrual health at secondary schools.
- 6 Where NICE guidance exists it should be followed – Trusts and CCGs need to be made aware of this.

Improve patient pathway:

- 7 Simple best practice pathway endorsed and mandated across the country – a clear patient pathway agreed and rolled out for endometriosis and fibroids.
- 8 Ensure appropriate incentivisation for treatment through payment mechanisms.
- 9 Encourage multi-disciplinary team working at Trust – to include interventional radiologists, gynaecologists and others.
- 10 Access to a clinical specialist nurse is an important way to improve patient understanding and patient care.

The RCN looks forward to working collaboratively on the findings of the report.

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## **Submission to the Inquiry by the RCN: (February 2017)**

### **Your name and the reason for your interest in this inquiry**

Carmel Bagness, Professional Lead Midwifery & Women's Health, Royal College of Nursing,

Our interest is around providing high quality care for all women, and concerns about the lack of a consistent approach to treatment and management of Endometriosis and Fibroids across the UK.

**2. Would you be happy for the group to use any comments you make in response to the questions below?**

**3. In your experience, what information is offered to patients who suffer from endometriosis regarding treatment options available?**

RCN has produced a Fact Sheet on Endometriosis, following the development of guidelines for Clinical Nurse Specialists in Endometriosis, as there is evidence from Endometriosis UK about the lack of consistent information, in particular the issue that it takes up to 5-7 years for accurate diagnosis in places.

the lack of consistent information, in particular the length of time for accurate diagnosis in places, is often linked to a lack of understanding about periods, and what is considered normal, by women, and healthcare professionals, who may be advising or diagnosing.

**4. In your opinion, what barriers exist to diagnosing patients who suffer endometriosis?**

Lack of understanding about the prevalence and extent of the disease,

Differential diagnosis is common, leading the lengthy timeframes for diagnosis

For the difficulties in diagnosis I think that it is partly due to complex and multiple symptoms and partly as women do not know what is normal or abnormal so may not present. There is not enough talk on normal periods so women put up with symptoms for a long time before presenting. The BSGE data base only looks at complex surgical but not at those who do not want to have surgery so it is limited.

Lack of understanding about the prevalence and extent of fibroids, women often do not seek help early, assuming symptoms are normal.

Differential diagnosis

For the difficulties in diagnosis I think that it is partly due to complex and multiple symptoms and partly as women do not know what is normal or abnormal so may not present. There is not enough talk on normal periods so women put up with symptoms for a long time before presenting.

**5. In your opinion, what barriers exist to treating and/or managing patients effectively who suffer from endometriosis?**

The main issue is the lack of consistency in the care offered from hospital to hospital.

Women who relocate can end up with completely different recommendations and care depending on where they are geographically. That combined with the lack of time afforded to appointments does not help women make an informed choice, as they are often encouraged to decide on the spot and not given the opportunity to discuss potential treatment with family members.

**6. In your experience, is every patient who requires treatment and/or management for endometriosis offered information about the full range of treatment options available?**

**No**, the main issue is the lack of consistency in the care offered from hospital to hospital.

Women who relocate can end up with completely different recommendations and care depending on where they are geographically. That combined with the lack of time afforded to appointments does not help women make an informed choice, as they are often encouraged

to decide on the spot and not given the opportunity to discuss potential treatment with family members.

**7. What do you feel needs to happen to ensure patients have access to information on all appropriate treatment options available for treating and/or managing endometriosis?**

Information that is offered regarding treatment is often tailored to what that local area offers and not necessarily what is out there nationally. The verbal and written information needs to be evidence based and a lack of NICE guidance/patient info specifically about fibroids means that clinicians may be selective in their discussions.

**8. What recommendations would you make to ensure endometriosis pathways best serve patients?**

We would encourage the Endometriosis centres, working together to provide a consistent approach to evidence based care, and the continuing use of and development of Clinical Nurse Specialist to support practice and aid consistent approaches to care

Finally there needs to be more research on treatments that are not contraceptive as well, as there is little to offer women who are wanting to conceive.

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Finally there needs to be more research on treatments.

**9. Please include any further information you have not been able to cover in the questions above related to the diagnosis and treatment of endometriosis.**

RCN have outlined the key skills and knowledge of the Clinical Nurse Specialist which only covers women in a specialist centre and once they have been diagnosed.

Women with this condition highlight the lack of psychological and emotional support, and the CNS can play a key role here in liaising between the woman and the MDT as well as acting as an advocate in situations where these women are unable, for various reasons to fight to have their voice heard, and for their right to choose the way their condition is managed.

Fibroids, a reluctance to talk about periods and what is normal and when to seek help.

Variable information from different sources that may not be appropriate. Different sizes and positions of fibroids need different treatments or none at all so it can be have to cover this in patient information. I think that there should be a NICE fibroid guideline that looks at other symptoms not just bleeding and more CNS posts

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