National Institute for Health and Care Excellence

Clinical Guideline: Endometriosis
Stakeholder Scoping Workshop
Thursday 4th March 2015

Presentations

The group were welcomed to the meeting and informed about the purpose of the day. The Stakeholder Scoping Workshop is an opportunity for stakeholders to review the draft scope and give their input into whether it is clinically appropriate.

The group received presentations about NICE's work, the work of the National Collaborating Centre for Women's and Children's Health (NCC-WCH) and the work of the patient and public involvement programme. The Chair of the guideline development group also presented the key elements of the draft scope.

Following questions, the stakeholder representatives were then divided into four groups which included a facilitator and a scribe. Each group had a structured discussion around the key issues.

Scope

General comments

- It was widely felt that infertility was too big an issue to ignore as the infertility guideline does not specifically address endometriosis
- Problems around delayed diagnosis leading to severe symptoms which make the condition more difficult to treat
- There is no standard practice management or pathway and clear guidance is needed for GPs and healthcare professionals
- The key points included identifying signs/symptoms on first presentation, how to monitor and when to refer the patient, use of diagnostic tests, staging system and timing of interventions

Section 1.1 Population

- Stakeholders felt that the population needs to include adolescents as delayed diagnosis is a big problem and has a large impact on quality of life
- Include "women with coexisting adenomyosis" in groups that will be covered, as a subgroup of women
- Include endometriosis in pelvis or abdomen

Equalities

The specific equalities issues discussed regarding endometriosis included:

- Learning disabilities and under-diagnosis – stakeholders felt this was true for all conditions and specific to endometriosis
- Age – adolescent girls may not feel comfortable discussing symptoms with a GP and might not realise that it's not normal
- All groups agreed that ethnicity should be considered, for example women who do not speak English may find it difficult to get the support they need and therefore have limited access to centres as well. This may also include factors such as religion/beliefs. From experience the group felt that women minority ethnic groups did not present for support and treatment to the same level as white British women
- Geographical location

Section 1.2 Setting

This section was not discussed in detail. The key comments were:

- The need for specialised endometriosis centres as a key setting

Section 1.3 Management

1.4 Key areas that will be covered

The Stakeholders discussed all the issues covered in the Management section of the scope. The main points included:

- Co-morbidities such as mental health issues, for example depression should be included
- Focusing just on pelvic pain is not sufficient as endometriosis requires specific treatment
- Fertility management not due to endometriosis is managed differently to fertility management with patients with endometriosis. Fertility due to endometriosis should be removed from fertility guideline and handled in endometriosis guideline
- Non-medical pain management topic should be broader to include diet, lifestyle and acupuncture
- Pain is an issue but sexual function, bloating and health-related quality of life are other issues that should be looked at
- Monitoring - the group discussed the need for clear guidance on monitoring of patients as there is a small group of women who may get treatment before diagnosis, and therefore the referral may be missed or incorrect. Overall, at the moment there is no clear pathway or guidance. The group suggested that monitoring should cover asymptomatic women, GP monitoring and cost effectiveness
- Importance of including extrapelvical endometriosis as it would be a short question (since it is rare) and no other guideline would cover it

1.5 Areas that will not be covered

Stakeholders discussed how the areas that are not covered are likely to be on guideline topics where there are cross-referrals.
General comments from the stakeholders included:

- Agreement with prevention not being covered as they do not think there is any evidence for the prevention of endometriosis
- Use of HRT in women with surgical menopause should be included

Section 1.6 Main outcomes

- Overall, the stakeholders were satisfied with the outcomes suggested, however felt that fertility should be included
- Time off work/participation should be included
- Quality of life - this outcome was also considered to be very important and should be included
- Recurrence - the stakeholders agreed that this term had to be clearly defined. Brief discussion of women's preference to have surgical or hormonal treatment depending on severity of condition

Section 1.7 Key issues and questions

The stakeholders did not discuss the review questions in depth. Their general comments included:

- The stakeholders suggested the question "what types of pain do we need to recognise that are associated with endometriosis?"
- There should also be a distinction of how to treat adolescents/young women as opposed to grown women. There may be questions from parents if you prescribe the contraceptive pill to adolescents/young women, for example
- For pharmacological treatment there was disagreement about analgesics as a treatment for symptoms rather than the actual condition. For surgical treatment, one member suggested that the word 'ablation' should be clearly defined because depending on the kind of treatment given the endometriosis is not necessarily completely removed, so this should be clarified and definitions provided for the different methods of ablation and the extent to which the endometrial cells are fully removed
- There was disagreement to whether information and support should be split into two sections. Although some agreed that many topics are closely linked. One member mentioned that there is a lack of information for GnRH treatment and therefore this should be included. In terms of support, the group suggested that factors such as treatment, diagnosis, relationships and fatigue are areas where most women will need help and support.

Section 1.8 Economic aspects

Health economics key issues:

- Limited information available on costs (in particular costs of specialist centres)
- economic aspect important in the 'when and where to refer' section as misdiagnosis and delayed treatment links with cost effectiveness
- Time to diagnosis
- Referral to specialist who is unable to treat patient so has to refer to another specialist (use of specialist centres)
- Laparoscopic vs open surgery

Guideline Committee composition

Stakeholders made the following recommendations for the proposed members of the Guideline Committee:

- An additional Consultant Gynaecologist in secondary care (District Hospital)
- An additional GP
- The radiologist to be a full member not an expert witness
- The suggested primary care members may only be needed for diagnosis issues

Stakeholders also made the following recommendations for expert witnesses:

- Expert on non-medical treatments
- Nurse specialist in pain management specialists
- Nurse working in primary care
- Paediatric gynaecologists
- School nurses
- Endocrinologist