All Party Parliamentary Group
Endometriosis

All-Party Parliamentary Group on the impact of gynaecology waiting times on those with endometriosis

9Th June 2025, 2pm – 3 pm, remote meeting via Zoom

Attendees

Parliamentary members and staff: Kirsteen Sullivan MP, Alec Shelbrooke MP, Bell Ribeiro-Addy MP, Katrina Murray MP, Markus Campbell-Savours MP, Cat Eccles MP, Angus Walker Stewart – Parliamentary Assistant to Kirsteen Sullivan MP.

Non-parliamentary stakeholders: Emma Cox, Ben Jones, Jo Campion, Carla Cressy, Debbie Shaffer, Anneliese Wecker, Vimbai Mandaza, Jodie Hughes, Natalie Megan Blake, Rachel Joseph, Sarah Smallbone, Stephanie Watson, Liz Hare, Rey, Aman Coonar, Sadie Were, Isobel Braithwaite, Sarah Beale, Elizabeth Gordon, Victoria Puckering, Kirsty Clarke, Annette Walton, Zoe Russell.

Guest Speakers

1. **Geeta Kumar,** Vice-President for Clinical Quality at the Royal College of Obstetricians and Gynaecologists.
2. **Dr Sharon Dixon**, GP partner and an NIHR Doctoral Research Fellow at the University of Oxford.
3. **Joanne Hanley:** Endometriosis UK's Specialist Advisor and Advanced Clinical Practitioner.
4. **Jen Moore:** Patient, and endometriosis and adenomyosis educator, speaker and campaigner.

Apologies: Andrew George MP, Ruth Jones MP, Jim Shannon MP, Kirsty Blackman MP, Catherine Fookes MP and Simon Opher MP. Sunaina Nechel-Maher, Andrea Ford, Keisha Meek, Anna Cooper, Gabz Pearson, and Gerry Gallott.

Key points

1. **Chair's welcome and introduction.**
    - Kirsteen Sullivan MP introduced the meeting and reported back to the group on the outcome of the EGM held on 6th May 2025.
    - In the EGM in May Bell Riberio-Addy MP stood down as chair and Kirsteen Sulivan MP was elected. All other officers remain in post.
    - Kirsteen Sullivan MP thanked Bell Riberio-Addy MP for her work.

2. **Geeta Kumar,** spoke about the College's work on gynaecology waiting times.
    - She started by summarising the extent of the problem, highlighting that long waits for gynaecology continue with 750,000 waiting to be seen across the UK.
    - She spoke about the need for government action to address this. She linked solving the current waiting times issues to the Government's 3 big shifts in healthcare: covering prevention, community care, and improved technology. These three shifts are set to the focus of the upcoming 10 Year Health Plan and she said that addressing waiting times can contribute to all three.
    - She set out some recommendations for Government, calling on them to make good on their previous promise to prioritise women's health and to focus on a renewed women's health strategy.

3. **Dr Sharon Dixon, GP** gave a GP's perspective on the impact of gynaecology waiting times on those with endometriosis.
    - Highlighted that diagnosis is important to patients but diagnosis shouldn't be the end of care.
    - GPs do a lot of referrals for onward care for those with endometriosis, but she feels there is a pressure to not refer. Which in turn causes a moral distress of holding people in primary care with very distressing symptoms.
    - She sees repeated cycles of discharge and re-referral for those with endometriosis. Is also aware of those that have even give up after experiencing this.
    - She was concerned about those that are seen quickly in a triage hub but then wait a very long time to see an endometriosis specialist nurse or other specialist.

4. **Jo Hanley, Advanced Clinical Nurse Practitioner** gave an Endometriosis Specialist Nurse's perspective on the impact of gynaecology waiting times on patients.
    - She said that long waiting times impact patient's quality of life, can lead to progression of symptoms and has impact on mental health and concerns about fertility
    - Has found that a high proportion of patients are contacting specialist nurses about their waiting times. Said that although they provide counselling not everyone has access to an Endometriosis Specialist Nurse so can't access their support while waiting.
    - She has observed that the demand for nurse specialists is growing too.
    - She reported seeing patients who are discharged and then need re-referrals when symptoms recur.

5. **Jen Moore, Patient representative** gave a patient perspective on the impact of waiting times.
    - Described her experience of pain, heartbreak and anguish and that sadly this was not unusual or unique and outlined the diverse, raw and real stories that she sees on social media.
    - Highlighted that a particular side of waiting is the crushing sensation of not being a priority or being believed. And patients are waiting too long because there are not enough specialists.
    - Found there was a lack of knowledge of endometriosis at all clinical levels and called for better clinical education and training across all specialists. Clinicians should know the warning sides and should ask routine questions about periods.
    - Said patients are exhausted and broken physically and mentally and feeling like nothing is changing.

6. **Discussion -** wide-ranging discussion on the topic including points on:
    - The need for a nationwide service specification and strategic approach to service delivery for those with thoracic and extra pelvic endometriosis.
    - Services to be looked at across the UK and not just a focus on England.
    - Endometriosis to be treated as the chronic, long-term condition that it is and not a series of acute episodes. Cited support from NCEPOD report and RCOG also supported this approach.
    - Suggestion to raise concerns at an upcoming Westminster Hall debate on long-term conditions.
    - The need for improved education among healthcare professionals.
    - More coordination needed between different specialisms and the importance of holistic care.

7. **AOB and summary of actions**
    - Follow up on the need for endometriosis to be recognised as a chronic condition.
        - APPG to explore who to write to about this.
        - Prepare PQs and raise in Westminster Hall debate on Long-term conditions to highlight the issue.
    - Support the development of UK-wide thoracic and extra pelvic service guidelines.
        - Secretariat to meet with Aman to discuss next steps.
        - Consider letter from APPG to Health Secretaries across 4 nations.
    - Raise awareness of endometriosis across medical specialties.

    - Contact Federation of Surgical Speciality Associations (FSSA), again with input from Aman.
    - Work with health professionals on the APPG to establish best route to influence increased content in medical school and CPD development.
    - Consider future APPG session on this.
- Raise awareness with employers about the chronic nature of endometriosis.
    - Encourage uptake of Endometriosis Friendly Employer scheme.
    - Write to trade associations.

For more information about membership please contact:
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