



Date/Time: 21st January 2025, 11am-12pm, Online

Attendees

Parliamentary - Ann Davies MP, Bell Ribeiro-Addy MP, Cat Eccles MP, Catherine Fookes MP, Kirsteen Sullivan MP

Non-Parliamentary Stakeholders - Amber Vodagel, Andrea Ford, Britteny Gibson, Callum James, Debbie Shaffer, Emma Cox, Faye Farthing, FOYAB, Gerry Gallott, Jasmine Hearn, Jen Moore, Jo Champion, Jodie Hughes, Katy Phillips, Liz Hare, Lone Hummelshoj, Natalie Greenwood, Neelam Heera-Shergill, Oliver Odonovan, Rey, Sarah Smallbone, Stephanie Watson, Veronique Griffith, Victoria Puckering, Zoe Russell

Apologies

Rebecca Smith MP, Andrew George MP, Alec Shelbrooke MP, Rachel Joseph, Marcia Stephens

1. Introduction – Chair Bell Ribeiro-Addy MP

- Welcome and apologies
- Introduced the topic of diagnosis – the wait times are too long, patients having to go through multiple and disconnected processes to seek a diagnosis and many end up on forums to get advice from others as they aren't getting answers from their health professionals and are waiting too long.
- This meeting is timely time due to Women and Equalities Select Committee report. The APPG can try to influence the Government to adopt their recommendations, particularly on setting a diagnosis target for endometriosis.
- There has been a recent debate on endometriosis in the workplace.

2. Current issues around diagnosis- Neelam Heera-Shergill, Founder of Cysters

- Neelam gave a brief overview of the disparities faced in accessing diagnosis from marginalised groups
- Neelam outlined the medical misogyny facing women of colour. We see the same stories and voices about diagnosis, yet there are underrepresented groups who have an even more difficult journey to diagnosis.
- Neelam outlined work currently underway with Endometriosis UK to do a study to hear more from those underrepresented voices.
- Neelam talked about work they are doing in Birmingham and Wolverhampton with refugees who need support in navigating the NHS, as well as the issues language

barriers create when describing symptoms, giving an example of the fact there is no word for endometriosis in Punjabi.

- Neelam requested help from the group to get their survey out widely so they can capture their unique journeys.

Action – Please contact smile@cysters.org if you can help

3. The NICE Guideline on Endometriosis partial update - Emma Cox, CEO of Endometriosis UK

- Emma outlined of updates and recommendations on diagnosis in the new partial review of the NICE Guideline on Endometriosis NG73, and what this means for diagnosing endometriosis.
- Endometriosis UK campaigned to get a full review. But NICE only did a partial review, citing a lack of evidence for a full review.
- Emma set out two areas of change:
 - 1) Fertility – guidelines were changed on approaches for cyst removal in order to maintain fertility
 - 2) Diagnosis changes
 - Guidelines now highlight the need for specialist ultrasound scanning so they are conducted by a specialist with training in gynaecological ultrasounds. However, this isn't yet available across most of the country so an area APPG could push.
 - Guidelines now recommend early ultrasound for anyone with suspected endometriosis.
 - Guidelines are now firmer about being referred to secondary when symptoms are detrimental to day-to-day life, and also if there is evidence of endometrioma. This is a recognition of the wider impact endometriosis can have on patients life.
 - Guidelines now clarify the parallel care needed for those with suspected endometriosis. This means patients should receive treatment from their GP while waiting for referral or scans, and should be given more information about support.
- Emma welcomed the updates as a step in the right direction but shared frustration that they were only partially reviewed and there is now some inconsistency with other guidelines such as pain management guidelines.
- Emma gave examples of things that need to be addressed in a full review, including endometriosis outside the pelvis (thoracic), endometriosis and menopause and non-pharmacological pain management.
- Emma gave a few examples of emerging diagnostic tests such as Endotech in France, a urine test in Hull and other tests too. So we need NICE to look again at diagnostics as new evidence emerges.
- There is potential for the women's health hubs and rapid test centres to play a role in implementing the new guidelines on ultrasound scanning.

4. Facilitated discussion and Q&A:

Bell Ribeiro-Addy MP facilitated a whole group discussion on the speakers contributions and the steps the APPG could take to encourage improvement to endometriosis diagnosis.

Discussion covered:

- The variety of diagnostic tests currently in trials/research and the need for the research gap on diagnosis to be filled. NICE and others to be more proactive in filling the research gap, or by using clinical agreement where there are gaps **(Action: APPG to write to NICE and request full review)**
- The need for a target diagnosis time on endometriosis because if there is a target it will be measured and this will improve the recording of endometriosis more widely.
- The need for education of primary care health professionals to put an end to normalisation of women's pain, and training for health professionals across the board.
- NICE guidelines implementation in Wales and Scotland and how Women's Health Hubs in Wales can improve diagnosis. **(Action: Bell offered to ask Parliamentary Question)**
- Diagnostic checklists for surgery and the promotion of existing resources/NICE guidelines on this.
- The challenges and timescales for training of sonographers.
- Cost impact of multiple scans and standards needed for specialist ultrasounds
- Women's health strategies and their status across the UK, and the need for a more strategic approach to service numbers/centres/staffing etc.
- Different diagnosis patterns for certain communities and groups being diagnosed as part of fertility treatment rather than pain symptoms.
- Education for women
- Poor coordination of results from investigations, scans and consultations leading to long diagnosis 'Nobody is joining the dots'..

5. Summary of agreed actions

- APPG to write to NICE about full review
- APPG to submit response to Spending Review Phase 2 and make case for investment
- Chair to table Parliamentary Question to clarify implementation of NICE partial updates in Scotland.

6. Upcoming business: Next meeting will be held on Tuesday 13th May 2025, 2-4pm