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Restructuring endometriosis care

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Women need better coordination between primary and secondary care

Endometriosis affects as many as 10% of women of reproductive age, or 190 million women globally.[1] It can cause debilitating chronic pelvic pain and infertility, with treatment, work loss, and healthcare estimated to cost £12.5bn annually in the UK alone.[2] The 2024 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report audited the care provided to 941 patients with surgically confirmed endometriosis and included the review of data from 120 general practitioners (GPs) and 623 specialists, alongside organisational data from 167 hospitals.[3] The report highlights examples of effective, timely, holistic, and patient centred care across all settings but also reminds us that we could and should do better for many women with endometriosis, throughout their care journey. Specific challenges discussed include the long timeframe to and difficulties in diagnosing and treating endometriosis, the lack of coordination between primary and secondary care, and the difficulty in accessing supportive services.

No clinical findings specifically correlate with a diagnosis of endometriosis, so GPs must often consider other conditions that have similar presenting symptoms. This may have contributed to the NCEPOD finding that 58% of women had multiple GP visits before investigations were undertaken or treatment was initiated.[4] Awareness training and education on diagnosing suspected endometriosis and managing it in the community are paramount but require collaborative support and advice from secondary care specialists.

Around 28% of patients in the NCEPOD report sought care in the private sector because of delays between GP referral and specialist review, creating inequities in access. Only 22 of 46 eligible patients were correctly referred to one of 63 British Society for Gynaecological Endometriosis (BSGE)[5] accredited specialist secondary care centres that care for women with severe endometriosis (defined as deep disease involving local organs or disease outside the pelvis). These centres have specialists in complex pain, urology, colorectal surgery, and

fertility, but access is driven by the severity of endometriosis rather than the severity of symptoms, which do not always correlate.

Superficial endometriosis can also present with significant symptoms and comorbidities and is generally managed by gynaecologists outside specialist centres. We must therefore consider moving towards a model of care that allows these patients to access the holistic services that the specialist centres currently offer. NCEPOD also identified fragmented episodes of care, where rapid and repeated discharge from secondary care necessitated repeated re-referrals and created gaps in ongoing support, with 75% of patients with a diagnosis needing to see their GP for a re-referral once endometriosis was confirmed.

The number of women with endometriosis successfully treated without surgery is unknown and not captured by the NCEPOD report. With more than half of patients who have had surgery reporting persistent or recurrent pain, gynaecologists must question whether surgery is always the most appropriate management. Well organised, multicentre, large scale, collaborative trials investigating the role of surgery in superficial and recurrent disease are currently underway.[6 7] Randomised surgical trials are, however, notoriously difficult to perform because of their methodological and logistical limitations, as evidenced by poor recruitment leading to the premature closure of a UK trial comparing surgery with medical treatment for deep endometriosis.[8] Oral gonadotropin releasing hormone antagonists such as relugolix[9] seem to be effective for endometriosis but require further evaluation before being incorporated into guidance.[10]

Multidisciplinary model of care

Much can be learnt from our European counterparts, specifically Germany and the Netherlands,[11] where surgical care is provided within a regional collaborative network with access to pain management, fertility, psychological support, research, and education. Translating this model into the NHS would involve the creation of endometriosis units within secondary care to triage GP referrals, diagnose endometriosis, and manage care for women with superficial disease. Women with suspected or confirmed severe disease could then be referred from these units to existing BSGE specialist centres, similar to the pathway for gynaecological cancers. This would mean that specialist centres could focus solely on treating severe endometriosis, allowing them to develop and maintain advanced surgical skills (often with colorectal and urological input) and expertise in managing the complex needs of these patients, holistically, across their lifespan. Restructuring services in this manner would allow for early multidisciplinary team input from complex pain,

psychological, and fertility services at both unit and centre level, ensuring access to holistic individualised care for all women living with endometriosis. Collaborative efforts would need to extend to audit, so that evidence based care is standardised nationally, as well as to research, to fill knowledge gaps in current practice.

The updated NICE guidance this month reflects these needs and aspirations. This includes calling for co-ordinated care across clinical networks through community and specialist settings for all people with known or suspected endometriosis and that all people diagnosed with endometriosis should have access to specialist pain multi-disciplinary teams.

Endometriosis must be reframed as a chronic condition in which many women will have symptoms that persist or recur across their lifespan, even if they have had surgical treatment. Surgery, therefore, cannot be the only answer, and greater emphasis must be placed on medical treatment, psychological support, and complex pain specialists. Primary and secondary care must collaborate to design and deliver the clear, cohesive, coordinated, and longitudinal care pathway that women with endometriosis desperately need and deserve.

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<jrn>1 Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020;382:1244-56. doi:10.1056/NEJMra1810764 PubMed</jrn>

<jrn>2 Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;27:1292-9. doi:10.1093/humrep/des073 PubMed</jrn>

<unknown>3 National Confidential Enquiry into Patient Outcome and Death. Endometriosis: a long and painful road. 2024. https://www.ncepod.org.uk/2024endometriosis/Endometriosis_A%20Long%20and%20Painful%20Road_full%20report.pdf</unknown>

<jrn>4 Dixon S, McNiven A, Talbot A, Hinton L. Navigating possible endometriosis in primary care: a qualitative study of GP perspectives. *Br J Gen Pract* 2021;71:e668-76. doi:10.3399/BJGP.2021.0030 PubMed</jrn>

<jrn>5 Saridogan E, Byrne D. The British society for gynaecological endoscopy endometriosis centres project. *Gynecol Obstet Invest* 2013;76:10-3. doi:10.1159/000348520 PubMed</jrn>

<jrn>6 Mackenzie SC, Stephen J, Williams L, et al. Effectiveness of laparoscopic removal of isolated superficial peritoneal endometriosis for the management of chronic pelvic pain in women (ESPriT2): protocol for a multi-centre randomised controlled trial. *Trials* 2023;24:425. doi:10.1186/s13063-023-07386-x PubMed</jrn>

<unknown>7 Saraswat L, Breeman S. Comparing gonadotrophin-releasing hormone analogues with repeat laparoscopic surgery for the treatment of recurrent pain following

surgery for endometriosis. ISRCTN48609976. https://www.isrctn.com/ISRCTN48609976</unknown>

<eref>8 Comparing medical management with laparoscopic surgery for the treatment of deep endometriosis. ISCRTN. 2023. https://www.isrctn.com/ISRCTN94462049 </eref>

<jrn>9 Giudice LC, As-Sanie S, Arjona Ferreira JC, et al. Once daily oral relugolix combination therapy versus placebo in patients with endometriosis-associated pain: two replicate phase 3, randomised, double-blind, studies (SPIRIT 1 and 2). *Lancet* 2022;399:2267-79. doi:10.1016/S0140-6736(22)00622-5 PubMed</jrn>

<eref>10 National Institute for Health and Care Excellence. Draft guidance consultation—relugolix-estradiol-norethisterone for treating symptoms of endometriosis. 2024. https://www.nice.org.uk/guidance/indevelopment/gid-ta10873]</eref>

<jrn>11 de Kok L, van Hanegem N, van Kesteren P, et al. Endometriosis centers of expertise in the Netherlands: Development toward regional networks of multidisciplinary care. *Health Sci Rep* 2022;5:e447. doi:10.1002/hsr2.447 PubMed</jrn>