



Aneurin Bevan University Health Board (ABUHB) response to provide written evidence for consideration in support of the Petition P-06-1242 to Improve Endometriosis Healthcare in Wales

Endometriosis service provision in ABUHB

ABUHB has been actively working to improve the provision and access to specialist endometriosis care within the Health Board. Ms Anita Nargund is the lead consultant for endometriosis, pelvic pain and minimal access surgery. In May 2021 we were pleased to welcome Joanne Kitt as Endometriosis Clinical Nurse Specialist (CNS) into the endometriosis team to deliver a high standard of care for women with endometriosis.

In May 2018 the NHS Wales Health Collaborative established 'The Women's Health Implementation Group' (WHIG) to address specific areas of women's health requiring urgent attention and improvement.

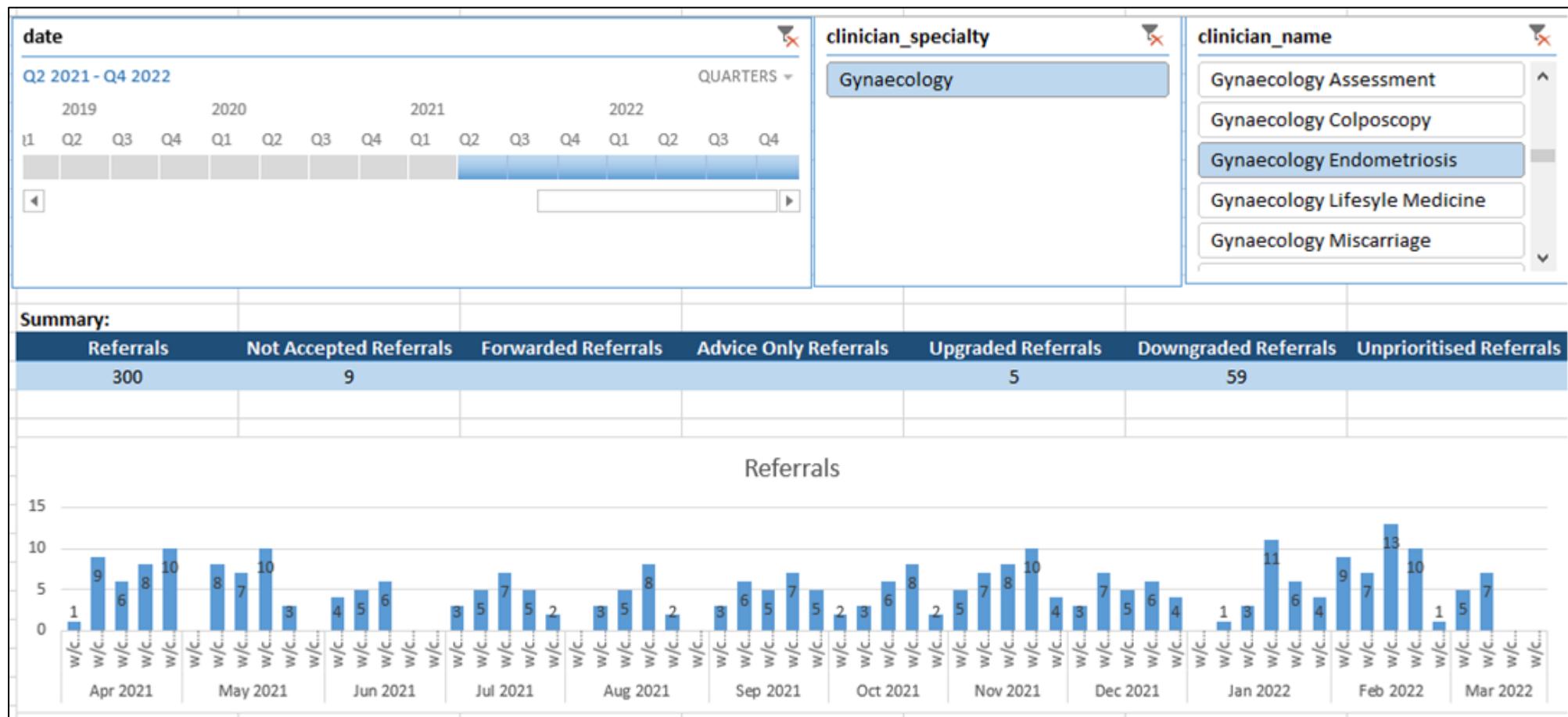
The NHS Wales Health Collaborative were directed by the Health Minister to deliver the recommendations from the following three task and finish reports as part of a five year programme of work:

- '[The use of vaginal synthetic mesh tape and sheets for stress urinary incontinence and pelvic organ prolapse](#)'
- '[Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures](#)'
- '[Report of the Welsh task and finish group for faecal incontinence](#)'

The CNS post is funded for a three-year period by WHIG.

All endometriosis referrals from primary and secondary care are triaged by Ms A Nargund, consultant gynaecologist, to be seen either in a consultant led or nurse led clinics initially.

Endometriosis referral data April 2021 to March 2022*



Attendance data for period April 2021 to March 2022*

	NEW attendances	Follow Up attendances	Email contacts related to Patient request to be seen or for advice; Post op care; Symptom advice; Advice further to MDT discussion
Anita Nargund	58	136	
Jo Kitt (CNS)	113	144	304

Waiting list position as at 22/03/2022

Due to the constraints created by the COVID 19 pandemic which resulted in a temporary suspension of face to face clinically non-urgent activity and the subsequent reduction in face to face capacity due to social distancing, the waiting list has been pressured.

	Total number on WL
NEW	162
Follow UP	113 (44 in Priority 1-3)

ABUHB has a dedicated consultant led endometriosis clinic every other Monday morning undertaken by Ms Nargund and CNS Joanne Kitt. In addition to the provision of the consultations, ultrasound scan and other diagnostic test like swabs, endometrial biopsy and insertion of Mirena IUS are undertaken.

The Health Board has received positive feedback from patients who have the support of the nurse during these appointments and for after care. A weekly multidisciplinary meeting is undertaken to discuss complex cases, and multispecialty multidisciplinary teams (MDTs) meetings are undertaken on a monthly basis for the holistic management of complex cases. The patients are informed about the outcome of the MDT. The MDT involves consultant gynaecologist, endometriosis CNS, physiotherapist, bladder CNS, Bowel CNS, pain specialist nurse, menopause CNS, psychologist.

The task and finish report (link below) recommended the following:

Endometriosis needs to be made a priority for both the training of GPs and on-going continuing professional development (CPD). Implementation group to facilitate. Primary care in Wales must be involved in implementing

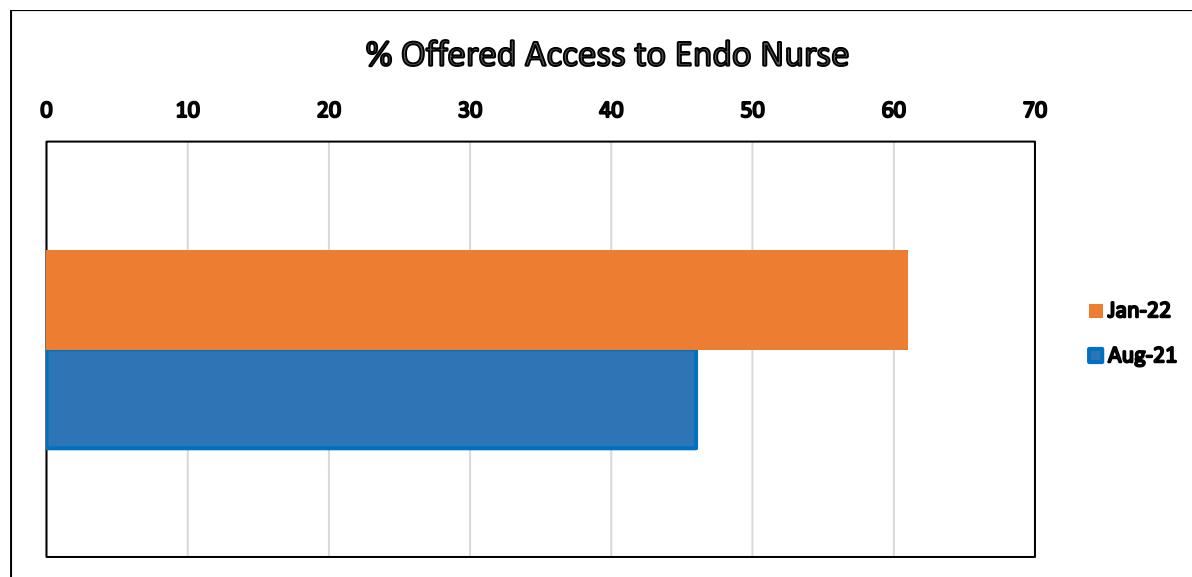
the adapted NICE guidance on endometriosis and local pathway development. (ref 3.3) Each Health Board will be responsible for training and appointing endometriosis nurse specialists who will assist in the education of GPs and practice nurses. (ref 3.3) Primary care should have direct access to resources such as psychological support, pelvic physiotherapy and pelvic pain management with relevant endometriosis expertise to assist women with a known, prior or suspected diagnosis of endometriosis. Health Boards should invest in the multi-disciplinary care of women with chronic pelvic pain / endometriosis. Services of this nature are of the sort that should meet the Prudent Healthcare principles of 'care closer to home' and with 'reduced variation'. Ideally, patients should be empowered to manage their own care where possible, so self-referral into these services should be facilitated.

[endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf \(gov.wales\)](https://gov.wales/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf)

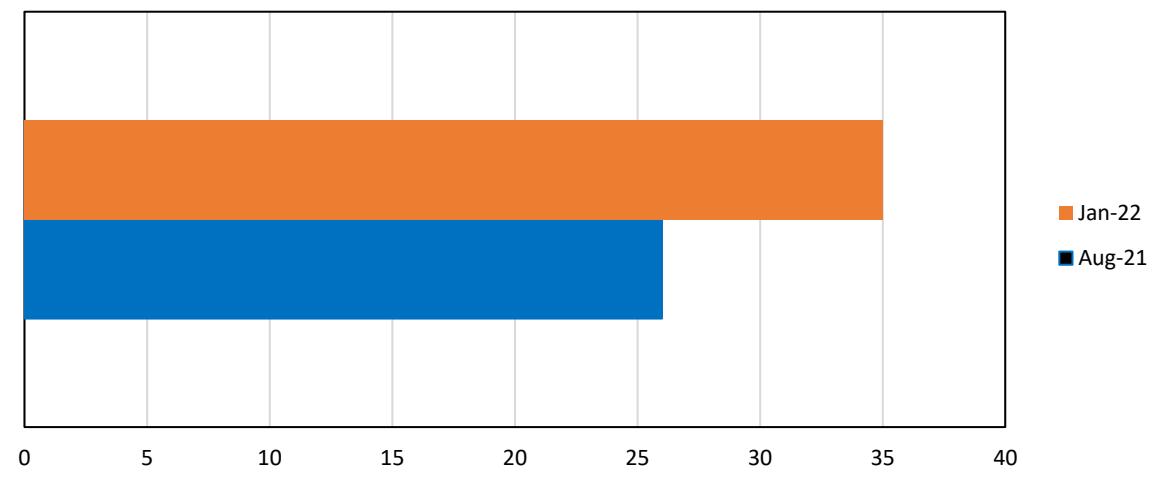
The Pelvic Pain MDT in ABUHB has been used as an example of a service that should be replicated across Wales and was a recommendation of the Vaginal Mesh for Wales published in 2018. The dedicated chronic pelvic pain consultant has recently retired without a replacement. The ABUHB Anaesthetic service have indicated that there are very few consultants with a special interest in chronic pelvic pain management and discussions are ongoing for appropriate representation at MDT.

The Health Board has developed the provision of Nurse Led Endometriosis clinics and have been measuring both the PROMs and PREMs and are so far receiving positive feedback.

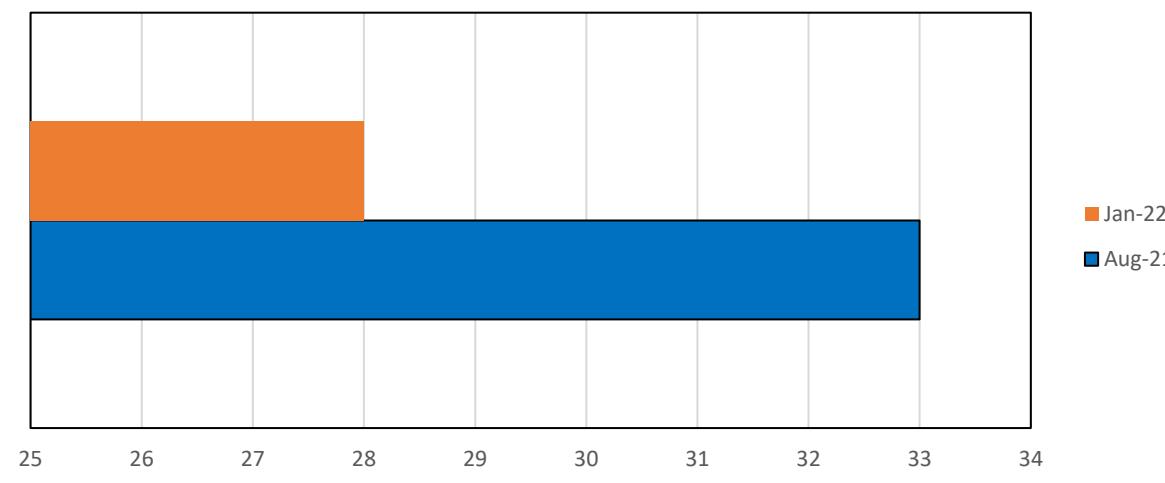
Data below references PREMS data comparison Aug 2021 and Jan 2022 (data comparison measured bi-annually)



% Received adequate post op advice

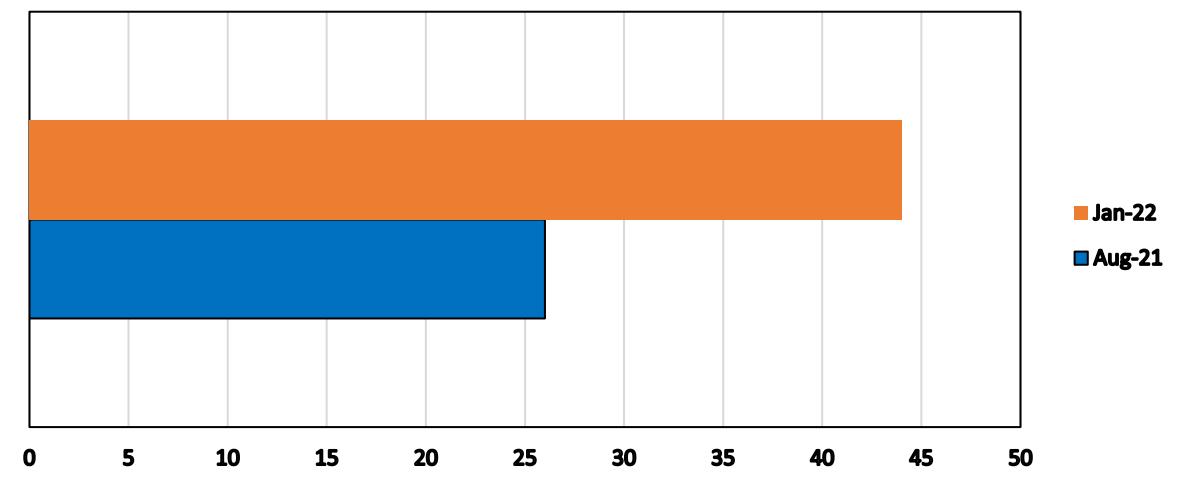


% Offered access to Pelvic Health Physio

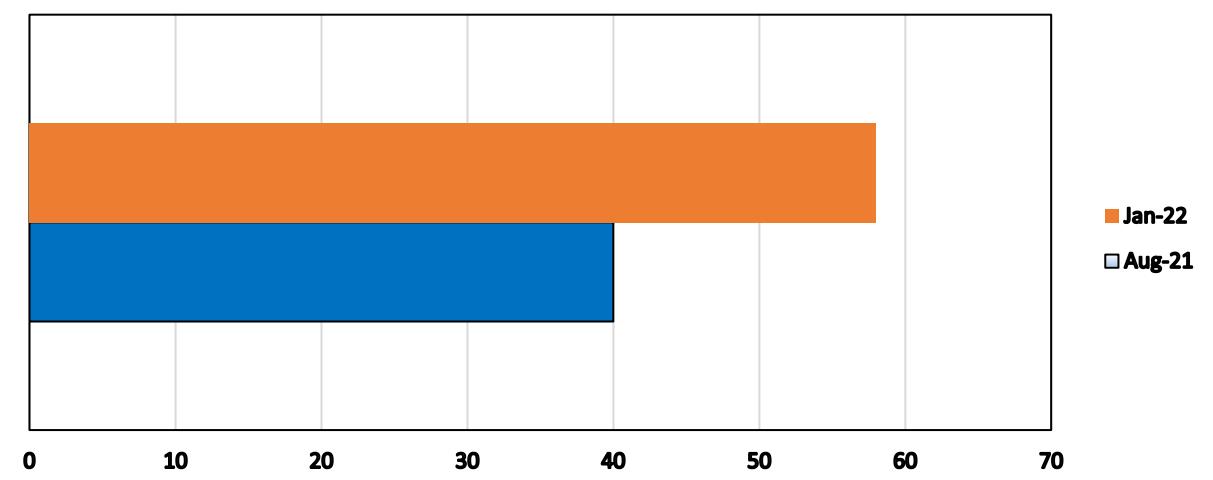


***The introduction of the Endometriosis CNS has enabled more appropriate referral to a specialist nurse for wider symptom support for management of the condition rather than was previously offered by specific Pelvic Health Physio. Further to assessment onward referral to pelvic health physio is made where clinically indicated.*

% Provided with adequate information regarding condition



% provided adequate advice on pain relief



Nurse led clinics offer face to face, virtual, and telephone consultations as the patient needs, and offers medical and conservative management of symptoms, and provides support and education. Investigations such as ultrasound scans can be done at face to face consultations. The aim is to provide effective communication, safe and timely management. We have established a dedicated email advice service which is open for patients referred to the endometriosis service. We aim to respond to the emails within a week and provide support. Currently we are working towards establishing a network and adopt a standardised approach across Wales.

We have established a dedicated pelvic pain referral pathway for symptomatic management of women with chronic pelvic pain. There is a dedicated ABUHB women's pelvic physio health website. This can be accessed via a QR code provided to women with an endometriosis diagnosis or chronic pelvic pain for self-help techniques.

This development/access has supported a reduction in direct referrals to the pelvic health physio from consultants**.

We have developed patient information leaflets on a multitude of topics such as pain management, dyspareunia painful intercourse, and postoperative care to provide information and support women with endometriosis. We regularly undertake teaching sessions for the staff for education. We have also started to work to establish the link with primary care providers and offer teaching and support regarding management of endometriosis and pelvic pain in the community. Our CNS has been asked to attend a community champion meeting to present and talk about endometriosis service and provide wider information to the community.

ABUHB has recently been recognised provisionally as a BSGE endometriosis centre. This allows us in enhancing the care being provided to the women with endometriosis, continuous medical education, maintaining and constantly improving the standards. We maintain a database in line with BSGE requirements.

Due to the unforeseen impact of COVID-19 pandemic there was some limitations in the provision of these services during the pandemic however, the Health Board is proud to inform that ABUHB is one of the few health boards currently offering services for routine benign gynaecology conditions.

We are happy with the progress we have made so far however we look to constantly improve our services, have a robust clinical governance framework, with regular audits of service provision, undertaking quality improvement projects, learning and education, interacting with our patients, seeking their opinion and undertaking validated quality of life questionnaires.

We will continue to work with our patients and colleagues, enhance the information provision with endometriosis cafes and use of powerful social media.

We constantly aim to achieve high standards required to gain BSGE accreditation as an endometriosis centre.

Further improvements for diagnosis and treatment of endometriosis should be prioritised nationally as the current average length of time to diagnose is 8 years (Wales and UK data). Examples are training in USS imaging and laparoscopic surgery. There are specialist centres in England such as UCL and in Southampton where the USS services are specifically designed to recognise early signs of endometriosis to avoid the need for diagnostic laparoscopies. Currently, the only centre which trains in particularly complex surgery is Cardiff, hence our aspiration to become a BSGE accredited centre.

In terms of monitoring the current services for women with endometriosis, improvements in coding would help. For example, waiting list data does not provide the functionality to specifically identify this cohort of 'suspected endometriosis'.

When a patient is listed for a laparoscopic procedure such as laparoscopic BSO, excision of endometriosis, adhesiolysis etc, there is no exact code match available on WPAS (the administrative date recording system used in ABUHB). Most women are listed for Laparoscopy (Staging Laparoscopy) T43.9.

In regard to the other elements addressed within the petition, other data that the Petitions Committee may be able to reference is the number of women using anovulant methods of contraception in Wales, the use of which may have non-contraceptive benefits for women and girls with endometriosis such as managing cyclical pain. We do not have a breakdown of this data across the ABUHB population.

In terms of education, we understand that within the curriculum, young people should receive information on conditions such as endometriosis in order to encourage access to health care for pelvic pain that interferes with normal daily functioning.

As a health board, we are committed to meeting the standards outlined on a number of guidelines as illustrated. However, we are wary of single condition emphasis in the face of current pressures and prioritisation challenges across medical and surgical specialities serving a complex population. We aim to deliver value-based healthcare across all ages and conditions.

Glyn Jones
25th March 2022