

**Endometriosis care in Wales:  
Provision, care pathway, workforce planning and quality and  
outcome measures**

Report prepared by the Endometriosis Task and Finish Group

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# ENDOMETRIOSIS TASK & FINISH GROUP REPORT

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## **Executive summary**

### **1. The current provision for women and girls with endometriosis in Wales**

Endometriosis is a common chronic condition prevalent in 10 % of women of reproductive age. There is a demonstrable lack of understanding of the condition amongst a considerable number of health professionals, resulting in significant delay in diagnosis, poor management of symptoms resulting in negative outcomes for those patients affected.

The subsequent results include women and girls giving up on receiving appropriate care, suboptimal educational and employment attainment, reliance on benefits, economic inactivity, breakdown of relationships and impact on quality of life. A cycle of deprivation ensues, with adverse childhood experiences incurred and significant detriment, and psychological morbidity caused to future generations.

Current service provision across primary, secondary, and tertiary care is not meeting need, resulting in lack of access to appropriate care for women across Wales. This variation leads to non-prudent use of resources and waste and harm for individuals and service providers.

### **2. A robust care pathway for the management of safe sustainable high quality and cost-effective endometriosis care including primary, secondary, and tertiary care, provided in all settings including remote and rural**

We propose a robust care pathway based on NICE guidance (<https://www.nice.org.uk/guidance/ng73>) using a life course approach to ensure that symptoms are recognised and responded to promptly and appropriately, as they emerge.

The adapted pathway begins with the promotion of menstrual well-being knowledge that is integral to the pastoral curriculum during primary and secondary education, and timely, efficacious response to symptoms in primary care. If management in primary care does not resolve symptoms, timely referral to a secondary care gynaecologist with expertise in endometriosis is required, and onward to tertiary specialist services within a BSGE endometriosis centre and/or fertility services as appropriate. Tertiary services should be commissioned by Welsh Health Specialist Services to ensure continuity, expertise and adherence to standards.

### **3. Matters relating to workforce planning and the education and training of staff involved in the provision of endometriosis services for NHS Wales**

At patient level, education should include online educational resources suitable for all ages to promote health literacy, symptom awareness, and early detection of endometriosis. Primary and secondary education providers need to be made aware of what constitutes normal menstrual health, so that they can aid in the identification of the early symptoms of endometriosis. We propose that an implementation group

assists in developing educational resources.

Each Health Board should develop a managed clinical network for women and girls with suspected or confirmed endometriosis based on NICE guidance (link to our amended nice document).

Health Boards should identify one or more consultant endometriosis leads to ensure the quality of diagnostics (including ultrasound and laparoscopic imaging) and local treatment as per the NICE guidance.

Each Health Board should provide at least one whole time equivalent endometriosis nurse practitioner to work with the identified consultant lead, not necessarily at the same hospital but across sites and primary care settings.

Tertiary provision for all the women of Wales must match need and this will require additional resources in order to meet BSGE and NICE quality standards comparable with NHS England. A detailed option appraisal as to how to achieve is provided in section 3.5.

#### **4. Quality and outcome measures to monitor the success of the services**

Endometriosis leads in each Health Board should collect the outcome measures as recommended by NICE. Additional, outcomes for Wales should include the following:

- Communication to both medical colleagues and patients, for example, copy of discharge note to the patient;
- Access to follow-up, responsive to patient need;
- Woman-centred clinical coding in primary and secondary care needs to be linked across the clinical network to facilitate the above;
- Harness Incident Reports to include missed and incorrect diagnosis, patient complaints, and serious incidents.

Priority areas for research funding include:

- Development of an effective educational symptom awareness tool;
- Evaluation of the follow-up processes after surgery and multidisciplinary approach to symptoms management;
- Evaluation of educational resources which are to be developed;
- On-going monitoring of patient outcomes over time. E.g. via self-reporting to a web resource.

## **Acronyms used in this report**

A & E – Accident and Emergency  
ART – Assisted Reproductive Technology  
BCUHB – Betsi Cadwaladr University Health Board  
BSGE – British Society for Gynaecological Endoscopy Endometriosis  
BSGI – British Society for Gynaecological Imaging  
C&VUHB – Cardiff and Vale University Health Board  
UHW – University Hospital of Wales  
CEO – Company Executive Officer  
COCP – Combined oral contraceptive pill  
CPD – Continuing Professional Development  
CPP MDT – Chronic Pelvic Pain Multidisciplinary Team  
DGH – District General Hospital  
EU – European Union  
FTWW – Fair Treatment for the Women of Wales  
GP – General Practitioner  
HRT – Hormone Replacement Therapy  
IBS – Irritable Bowel Syndrome  
NICE – National Institute for Clinical Excellence  
NWIS -- NHS Wales Informatics Service  
POP – Progesterone only pill  
RCGP -Royal College of General Practitioners  
RTT - Referral-to-Treatment  
WCP – Welsh Clinical Portal  
WFI – Wales Fertility Institute  
WG – Welsh Government  
WHSSC – Welsh Health Specialist Services Committee  
US – Ultrasound scan

# **1 Introduction**

## **1.1 What is endometriosis and how is it managed**

[1.1 What is endometriosis?: symptoms]

Endometriosis is a chronic disease that affects 1 in 10 of the female population of reproductive age. It can present soon after puberty and can still have an effect on women who are post-menopausal.

Endometriosis occurs when tissue similar to that lining the womb is found elsewhere, often but not exclusively, in the pelvis. This can cause multiple symptoms including painful periods, cyclical pelvic pain, sometimes irregular or heavy periods, painful intercourse, bowel and bladder pain, female sub-fertility, and chronic fatigue.

Endometriosis symptoms such as severe dysmenorrhea (menstrual pain), inter-menstrual pain, dyspareunia (pain during sexual intercourse), painful defecation, pain on passing water (dysuria), back pain, fatigue and infertility have a profound negative impact on quality of life.

Some mild menstrual pain occurs in a large number of women but should not disrupt her social, education or employment lifestyle. Mild menstrual pain should be relieved by mild analgesia. Pain that is subjectively defined as more than above give a high probability of endometriosis. Sadly, this is often trivialised due to lack of evidence based knowledge of the healthcare provider.

Chronic pelvic pain is a common symptom of endometriosis and is frequently refractory to hormonal and surgical treatments. The association between endometriosis stage and severity of pelvic pain symptoms is marginal (Vercelini 2007). Women with endometriosis, have more frequent menstrual pain and incapacitation than chronic pain patients without endometriosis (Hsu et al 2011).

Pain is an unpleasant subjective experience arising from the central nervous system that normally alerts and protects the body from potentially noxious stimulus (Osterweis et al 1987). Chronic pain, however, is pathological in itself, and often persists well after an inciting stimulus or injury has resolved<sup>4</sup>. It is a result of functional rearrangements of the central nervous system that both sustain the perception of pain and facilitate its expansion to distant regions (Latremoliere et al 2009). Given that endometriosis is a disease in which hormonally dependent, inflammatory, ectopic endometrial lesions engage the reproductive, endocrine, vascular, musculoskeletal, and neuronal systems, there are several factors that may contribute to chronic pelvic pain<sup>5</sup>.

Endometriosis affects women of all ages, ethnic backgrounds and social class. The annual socioeconomic costs are estimated in the EU to be 30 billion euros (European Endometriosis Alliance, 2006). In Ireland, USA, UK and Italy the average extra cost/week/woman to the employer is \$200-\$250 in absenteeism. NICE estimates annual cost of delayed diagnosis / treatment as being considerable. With Welsh patients waiting, on average, one year longer for appropriate care, this incurs an

additional cost to the Wales economy. Although pelvic pain conditions create a major fiscal and human burden they are not acknowledged in the WG relevant health policies (*'A Revolution from Within: Transforming Health and Care in Wales'*, 2018) Despite the above findings, and although chronic pain conditions are considered illnesses, they are not yet recognised and dealt with as disease, either in healthcare or society in general.

### 1.2 how is endometriosis diagnosed?

Diagnosis is sometimes difficult because the symptoms of endometriosis vary so much; different women have different symptoms or some women have no symptoms. The symptoms can be similar to pain caused by other conditions such as irritable bowel syndrome (IBS) or pelvic inflammatory disease. Painful periods can often be mistakenly normalised by family-members, as endometriosis is often hereditary.

Endometriosis is diagnosed (following appropriate history and examination raising suspicion) by finding typical cysts on an ultrasound scan, visualising it in the posterior vaginal fornix on speculum examination, or visualising the disease at diagnostic laparoscopy (placing a small telescope through the navel under anaesthetic to visualise the abdominal contents).

It has been widely recognised there can be a delay in both diagnosis and effective treatment of endometriosis symptoms. According to our survey of patients across the UK, patients treated by the Welsh NHS patients wait, on average, a year longer for a referral to a gynaecologist than their English, Scottish or N. Ireland counter-parts (about 8 years compared to 7), require more visits to obtain a diagnosis (about 26 visits versus 20 visits) and more often felt like giving up on trying to get their symptoms explained or diagnosed (See Appendix 5 and 5a for survey report).

In addition, evidence shows that 46% of endometriosis patients need to see five or more doctors before they reach a correct diagnosis (Denny, 2009; Mihalyi et al. 2010). Delays arise from patients not acting on their symptoms, and health professionals not responding appropriately to symptoms reported to them (Ballard et al 2006)

Receiving the definite diagnosis is a critical stage in the woman's illness trajectory as it results in both biomedical treatments, and access to those support and advisory networks developed by both other women with the disease and dedicated charitable organisations. A diagnosis is also critical for a woman's career where unexplained absences can result in loss of pay or sometimes loss of a job. Without a diagnosis, those in education cannot get dispensation for missed course work or impact on exams.

### 1.3 how is endometriosis treated/managed

Treatment includes analgesia, hormonal manipulation using contraceptive preparations, and laparoscopic surgery to destroy or excise the disease. Other options to manage symptoms include exercise, physiotherapy, diet, psychological therapies, and counselling.



Analgesia works mainly by reducing inflammation or neuropathically. There are many types of medication, ranging from over-the-counter preparations, to treatment prescribed by a specialist pain management team.

Hormonal treatments, including the combined oral contraceptive pill (COCP), an intrauterine progestogen system (Mirena IUS) or progestogen injection, progesterone only pill (POP)/mini pill or contraceptive implant reduces or stops ovulation, therefore either stopping periods or making them lighter and less painful. Pituitary suppression with Gonadotrophin releasing hormone analogues with add back combined Hormone Replacement is another effective alternative, which centrally suppresses ovulation

The type of surgical treatment recommended depends on site and extensiveness of the endometriosis. Surgery may be done at the time of the diagnostic laparoscopy or may be offered later. Success rates vary, and further surgery is sometimes needed. If the endometriosis is severe, the patient needs to be referred to a BSGE recognised endometriosis centre where a multidisciplinary specialist team comprising gynaecologist(s), bowel surgeon, urologist, radiologist, specialist(s) in pain management and specialist nurse is in place. A central register of patients so treated indicates that such surgery is safe and effective with sustained improvements in health-related quality of life and symptoms over 2 years following surgery (Byrne et al 2018)

The encounter of these patients with health care systems is often shadowed by poor experience, stigmatisation and significant delays in diagnosis and poor management. This reflects deficient knowledge and imprecise assumptions among patients and their health care professionals.

## **1.2 How was this review instigated**

### **I. Summary of FTWW Statement**

Fair Treatment for the Women of Wales (FTWW) was set up at the end of 2014 following the founder (Deborah Shaffer)'s wholly unsatisfactory experiences as an endometriosis patient in Wales: this included a 26-year diagnostic delay and subsequent inability to access specialist care. The organisation has an online group currently in excess of 600 members from across Wales, a figure which can be considered the tip of the iceberg in terms of numbers affected.

Research conducted by FTWW into its members' experiences revealed that the diagnostic delay was, on average, around 10 years and that patients were routinely dismissed by healthcare professionals up to and beyond that point, and frequently told that symptoms were psychosomatic or 'normal'.

Patients with confirmed disease were not being referred in any consistent way to specialist centres and, in fact, most GPs and local gynaecologists were unaware that such centres existed or that their health board(s) had made some provision for such referrals. This mirrors the findings of the UK wide endometriosis charity, Endometriosis UK. <https://www.endometriosis-uk.org>

Given this evidence and that noted on the disparities in care and choice offered to patients living in England compared to those in Wales, FTWW submitted a report into the issues to CEO of NHS Wales, Dr Andrew Goodall (appendix 1 & 2). Subsequently, this Task & Finish group was created, and FTWW was invited to represent patients across Wales, along with representatives from Endometriosis UK.

### **1.3 Establishment and working of the T & F group**

The group was established as a multidisciplinary committee with considerable lay representation derived from FTWW and Endometriosis UK, an endometriosis nurse practitioner, a physiotherapist, an academic clinical psychologist, a consultant anaesthetist specialising in chronic pelvic pain, a consultant gynaecologist representative from 6 Health Boards, and the director of Wales Informatics Service. (membership list Appendix 3).

The first meeting took place in March 2017 and was held at Welsh Government (WG) with WG administrative support.

Sub groups were established and met between main meetings. Their briefs were:

- Care Pathways
- Pain Management
- Information Technology
- Training needs across a wide remit

Six meetings of the full working group were held.

### **1.4 The process followed**

Three surveys and a workshop were conducted:

- A) Gynaecologists from 6 health boards in Wales;
- B) Patients from across the UK with confirmed diagnosis of endometriosis, and a comparison group of women with undiagnosed pelvic and gynaecological symptoms not diagnosed as endometriosis and an in-depth arts-based workshop of women with endometriosis living in Wales;
- C) Women's Health Physiotherapy Services across Wales

*Survey A* The Welsh consultants' survey Appendix 2 was conducted to assess the availability of services and scope of consultant practice in Wales. Obstetrics & Gynaecology Consultants in Wales were sent a questionnaire on their practices on patients with endometriosis via the Unit's clinical directors.

The questions were devised using the standards set from the NICE guidance on Endometriosis, with the aim of evaluating implementation of these standards in those services currently available to patients in Wales. (Survey questions in appendix 4)

*Survey B* was an online questionnaire for patients, designed to capture the patient experience in Wales and draw comparisons with patients across the rest of the United Kingdom. This was facilitated by Cardiff University and disseminated via email and social media by FTWW and Endometriosis UK, resulting in 136 / 422 respondents living in Wales/Other UK, and 175 women with undiagnosed pelvic and

gynaecological symptoms as comparison group (where relevant). (Survey Report appendix 5 and, questions Appendix 5a). In addition, a DrawingOut Health workshop with 14 women diagnosed with endometriosis was carried out to generate a deeper understanding of symptom experience and help-seeking for women in diverse areas of Wales (January 2018).

*Survey C* was designed to assess provision of physiotherapy across Wales. Physiotherapists were surveyed regarding their availability, knowledge, areas of specialism, and provision of dedicated pelvic pain physiotherapy.

Key findings from all three surveys can be seen in Section 2 and the surveys are provided in appendices 4,5 (5a) and 6.

## **2. Assessment of current provision of services for women with endometriosis in Wales**

Health professionals, researchers, patients, WG representatives, and voluntary groups were consulted to articulate the issues and barriers faced in providing or accessing endometriosis services in Wales. The results of the three surveys described previously also contributed to this assessment.

### **2.1. Women and girls with pelvic pain and endometriosis**

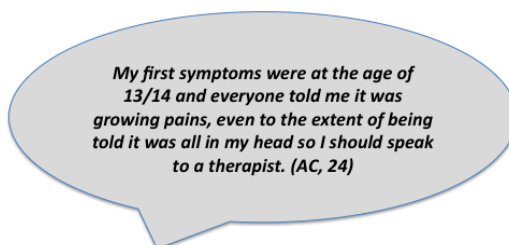
#### *2.1.1 Lack of education about endometriosis*

Patient quotations in shaded boxes are reported to us via FTWW. Quotations linked to drawings are from arts-based workshop.

There is a current lack of information for young women with potential endometriosis symptoms, including insufficient education programs in schools to raise awareness of the condition. Our survey shows knowledge of endometriosis is poor among women with undiagnosed pelvic and gynaecological symptoms that could potentially be signs of this disorder. Furthermore, there is a concurrent lack of signposting to the services available for advice and treatment.

Currently there is minimal evidence of a robust education programme to raise awareness of endometriosis at secondary and further education levels. As a result, there is a lack of awareness of the condition and its symptoms in women at all ages starting from childhood and adolescent age. Aside from lack of education, another key factor is the normalisation and acceptance of menstrual pain by patients themselves and family members, friends, employers, and the public at large, resulting in delay in help-seeking.

Our survey indicates that average age of symptom recognition is 20 to 22 years, but presentation is 1 to 2 years later. Among Welsh participants 65% reported that doctors had normalised their experiences in the early days of help seeking (63.5% in rest of UK).

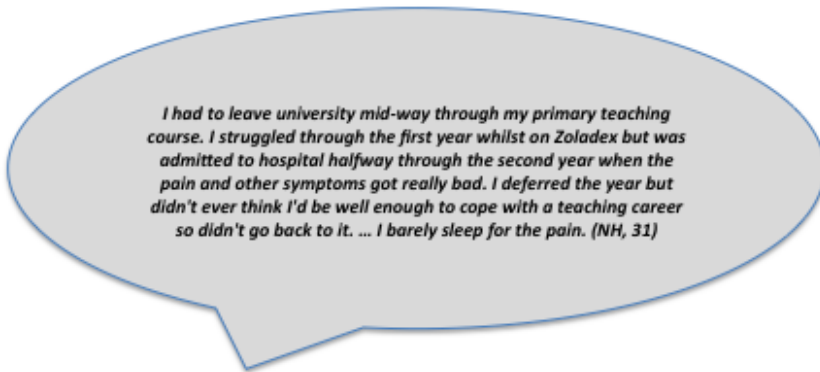


Charitable organisations such as Endometriosis UK <https://www.endometriosis-uk.org> and FTWW <https://www.ftww.co.uk/> provide information and support. These organisations are often the first point of contact on the patient journey and, as such, need to be consistently signposted by both educators and healthcare providers. There are inequalities in accessing services based on geographical location (Wales versus Other UK), ethnicity, language, age, and socio-economic group.

Provision of education and improved awareness is important. Symptoms have a negative impact upon the individual's productivity and finances. Survey participants in Wales had more disease burden, with more symptoms, of greater frequency and severity. It could be that greater disease burden means that women in Wales have more complex disease that is more difficult to diagnose. However, we would argue the reverse; greater disease burden is a consequence of inefficiencies in the care pathway and long delay in diagnosis that allows the disease to progress to a worse state. The majority of participants in Wales and other parts of the UK reported unsatisfactory early medical consultations that minimised or normalised their symptoms, that subjected them to unnecessary repeat testing, and that often led to incorrect diagnoses or ineffective first treatments requiring further, more invasive treatments at a later date.

Together these findings suggest that the current care pathway is not efficient, and attracts additional costs to the National Health Service in Wales through physical disease progression and through additional health services to manage suffering (e.g., depression, pain management) and potentially through other lost opportunities. Indeed, our survey participants living in Wales were twice as likely to be unemployed despite being as educated as their counterparts in other areas of the UK. This can result in the need to claim unemployment and disability benefits. Endometriosis makes it hard for women affected to stay in employment, as employers fail to recognise the impact of the condition or how to make appropriate reasonable adjustments (for example, home-working). Delay in diagnosis makes it more difficult to access appropriate income support.

One patient described this journey:



Finally, survey participants in Wales were more likely to feel like giving up on having their symptoms explained or diagnosed compared to other UK residents with endometriosis.

A major theme in the arts based workshop in Wales was the perception of suboptimal care experienced. Women described the healthcare they had received as poorly organised, felt they had been subjected to repetitive and unnecessary tests and often exposed to harmful doctoring (e.g., lack of empathy, patronising attitudes).

Participants from the arts based workshop described and illustrated their healthcare experiences in Wales in the following way:

<p>YC: I kinda wanted a way to visualise just (the) 'bla bla bla bla bla' so I kinda just wrote that and then started writing like just other things that doctors have said to me in the past like it's not endo it's IBS it's not endo you've got an STD it's not endo you just need to stop sleeping around -- when I was like fifteen and a virgin at that point (.) ... do you wanna try this treatment do you wanna try that do you wanna be shoved on this lovely bit of menopause for a while ... I'm just tired of hearing all of this basically</p>	
<p>RJ: mine is basically a brick wall with a big no on it and a dead end sign (.) and a thousand pound weight that I'm waiting to drop on my head and me just saying please help and then jail bars because I feel like I'm just punching the wall and beating my head against the wall (.) um because- and- and fighting for something that I shouldn't have to fight for</p>	

IL: so it's little me- um with a big question mark above my head looking at a big road sign which kind of leads to the GP first and then to the various departments in which you get passed around and there's no actual route out of that you just go round in the same thing (.) so your gynae will refer you to gastro who may in turn refer you to your GP who may send you back to gynae who might send you to ENT and it's just- you just kind of get lost somewhere in that (.)

...um and then the second one is a bit metaphorical (.) there's me my house is burning down, things are flooding, there's bricks, there's tiles falling off everywhere and I'm shouting help my house is falling down and the fireman says ... but THIS brick looks fine (.)

... one person (doctor) who might look at a very very specific part of you and go well that's fine so you go back on the tread



### 2.1.2 Variable and suboptimal interaction with healthcare providers

The surveys revealed significant variability in experiences of healthcare provided in Wales, including:

#### a) General Practitioners

Variability in GP response to, and initial management of, patient symptoms.

Clinicians in the advisory group acknowledged that there existed many GPs with good endometriosis awareness. Survey respondents reported diverse experiences in the primary care setting (n=136 living in Wales, but similar pattern among 433 participants in other parts of the UK):

- Patients told that pelvic pain is 'normal' (65.4%)
- Symptoms not taken seriously or attributed to mental health (e.g., stress, anxiety, depression) 24.3%
- Patients dismissed: survey evidence suggests an average of 26 GP consultations before referral to a gynaecologist, with some women not finding a solution in primary care at all.
- Patients repeatedly misdiagnosed, (34.6%) or having ultrasound scans that fail to detect endometriosis (33.8%).
- Patients with clearly indicative symptoms not referred to gynaecology or not acted upon (9.6%).
- Patients repeatedly sent for inconclusive / unwarranted tests, including bloods, endoscopies, x-rays, STI swabs (25%)
- Repeated courses of ineffective and / or inappropriate treatment e.g. IBS medications, antibiotics, pain relief, anti-depressants



- Reported delay in referral from GP to diagnosis of 7.56 years versus 6.53 in other UK; from diagnosis to treatment delay was much shorter about 6 months in Wales and three months in the rest of the UK.

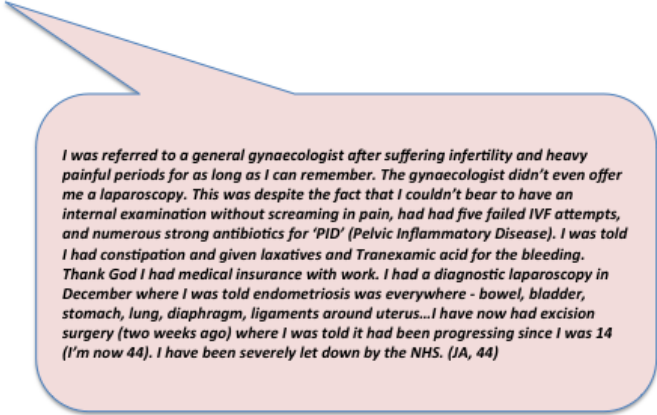
*I was repeatedly put on an antibiotic (over) a period of years ... because the GP insisted it must be a pelvic or urinary tract infection ... when I was given ultrasounds they always showed inflammation but weren't followed-up, apart from more antibiotics. I finally went ... (to a) gynaecologist for a proper diagnosis. (LS, 30)*

*At the age of 16 (1998) I collapsed at college (had tests with inconclusive 'all fine results' and discharged a few days later. ... pattern was repeated every month over the next year ... general surgeon (did) a second, joint laparoscopy ... returned an opinion of 'all clear' but the general surgeon ... diagnosed endometriosis ... (nevertheless consultant) discharged me ... to the care of gynaecology who in turn referred me to psychiatry with the advice that I should get pregnant to cure myself. (BE, 36)*

According to the patient groups, surveys and workshop, numerous factors could contribute to the heterogeneity and dissatisfaction of patient experiences at primary care. There could be a lack of GP education on disease recognition, diagnosis and first line management options. The multiplicity of symptoms reported by these patients could make appointments time-consuming, difficult to schedule, and patients complex to treat. The lack of a uniform guideline to assist GPs with referral processes and pathways could result in poor-quality, often inappropriate, referrals for patients. There could be a lack of GP resource and access to ancillary services in the community, for example, pelvic pain management, pelvic physiotherapy, and psychological support. Some women could have difficulty in discussing the problem with male doctors. In addition, a lack of symptom recognition by A&E doctors could result in repeated attendance for unscheduled care, and delay in referral to gynaecology.

## b) Gynaecologists in Secondary Care

Services for endometriosis provided within gynaecological services is sub-optimal.



*I was referred to a general gynaecologist after suffering infertility and heavy painful periods for as long as I can remember. The gynaecologist didn't even offer me a laparoscopy. This was despite the fact that I couldn't bear to have an internal examination without screaming in pain, had had five failed IVF attempts, and numerous strong antibiotics for 'PID' (Pelvic Inflammatory Disease). I was told I had constipation and given laxatives and Tranexamic acid for the bleeding. Thank God I had medical insurance with work. I had a diagnostic laparoscopy in December where I was told endometriosis was everywhere - bowel, bladder, stomach, lung, diaphragm, ligaments around uterus... I have now had excision surgery (two weeks ago) where I was told it had been progressing since I was 14 (I'm now 44). I have been severely let down by the NHS. (JA, 44)*

A lack of specialist teams could mean fewer people receiving optimal care. With the exception of the BSGE endometriosis centre in Cardiff there are no dedicated endometriosis and pelvic pain clinics in Wales. Experience has indicated that endometriosis often has subtle appearances and distorts pelvic anatomy. This subtlety means endometriosis is not always easy to recognise by general gynaecologists and could result in the diagnosis being missed. Research should aim to clarify to what extent each of these factors contributes to heterogeneity healthcare experiences and how these could be addressed to improve the provision of care for endometriosis.

Most gynaecologists will undertake a diagnostic laparoscopy and then offer medical management (8/33 survey respondents) or, alternatively, ablate disease (13/33 survey respondents) with little long-term benefit. These approaches result in repeated surgery as compared to complete excision of the disease. This is not cost effective and fails to improve long-term quality of life.

Of the gynaecologists surveyed, the majority (20/36) were not sufficiently skilled or confident to excise endometriosis, particularly if the disease was overlying the ureter, bladder, diaphragm or bowel (30/34).

Given the estimated 150,00 women affected in Wales there is an insufficient number of highly skilled gynaecologists trained in intermediate and advanced excisional laparoscopic surgery based on the survey evidence above



A number (11 of the 34 who responded to the question) of gynaecologists surveyed are utilising hysterectomy / subtotal hysterectomy / oophorectomy without excision of remaining disease as a treatment for endometriosis which is contrary to NICE recommendations and has potentially negative long-term health implications and associated costs

*I had a total hysterectomy and removal of ovaries at age 30 as a 'cure' for endometriosis. I was told that I would be able to just get on with my life and put an end to symptoms. However, 4 months later, the pain came back. Since my 'cure', I've had a further 7 surgeries with general gynaecologists (12 in total) where endo has been 'burned off'. I have endo all over my left ureter, bladder, bowel and peritoneum. I have intermittent declining kidney function and debilitating pain, but I am now under the specialist team in Cardiff and waiting for further surgery that I hope will be the final one. My whole life has been controlled by this dreadful illness. I've struggled to work, had to leave my teaching career as I couldn't stand in front of a class because of the pain. I have on-going issues with my bones and fibromyalgia too as I have no hormones. I've felt very alone having gone through surgical menopause at such an early age and I've lost many friends. No-one should have to battle through life like this.  
(JARG, 50)*

Prior to the recent NICE Guidelines, there were no clear guidelines as to which women should be referred to tertiary care, and for women in Wales, where that would be situated, depending on patient location.

### c) Tertiary endometriosis services

British Society for Gynaecological Endoscopy Endometriosis (BSGE) centres are accredited departments equipped to deal with complex regional referrals ensuring complex cases are treated appropriately across the UK.

Centres have access to colorectal surgeons, urologists, pain specialists and a specialist endometriosis nurse. The centre compiles information on surgery performed and these data are entered into a national database with electronic follow up of cases.

In England and Scotland there are currently 103 gynaecologists in 61 endometriosis centres, compared to just 3 gynaecologists in one centre in Wales, all of whom also practice Obstetrics. The current population of Wales is 3.1 million, whilst England and Scotland have a combined population of 59 million. This represents a deficiency of 3 specialist endometriosis gynaecologists in Wales.

The BSGE endometriosis centre in Wales (Cardiff) is inadequately funded and has no additional source of funding. This chronic funding state has led to long waiting times for the most complex surgery, far in excess of the 36-week Referral-to-Treatment (RTT) target set by Welsh Government.

The Cardiff centre relies on rectal endoscopic ultrasound scanning to triage women with disease between the bowel and the cervix to indicate whether a colorectal surgeon is required for surgery or whether the gynaecologist can safely operate alone. This aspect of the service is dependent on one radiologist and is not possible when the radiologist is unavailable (e.g., annual leave, illness), leading to greater unnecessary demand for joint gynae-colorectal procedures due to lack of triage.

Currently, the Cardiff centre is expected to provide care for complex patients throughout South Wales, of which, one third are from outside of Cardiff and Vale. These unfunded patients require several hours of theatre time, for which there is insufficient infrastructure, physical capacity, suboptimal theatre equipment with under-resourced input from gynaecologists, colorectal, urological and thoracic surgeons.

In England, such surgery carries a tariff that reflects the complexity of the procedure. Tariffs range from £5.5K to almost £12K. See appendix 7 for more detail. In Wales, the tariff system is not implemented and funding is based on historic block contracts. There is therefore a lack of financial incentive to undertake complex joint procedures. Indeed, the activity of the BSGE endometriosis centre is clearly a financial burden for the department of Obstetrics & Gynaecology, and the Cardiff and Vale University Health Board. The lack of financial incentive may also be a factor in other Health Boards deciding not to achieve BSGE endometriosis centre status. This financial situation is unsustainable.

Unfortunately, to manage increasing demand, a number of patients are now being declined. Currently one or two women a month are being turned away as there is insufficient information in the referral to indicate that they need complex surgery. This means that they may be turned away until the disease has progressed. If these patients were managed well early in their disease progression, the complexity could be less and the surgery less costly overall. (Nice endometriosis guideline Health Economics Appendix Pages 53 – 59)

*I was diagnosed in 2000, aged 23, after not conceiving. Diathermy ablation was performed, and I got pregnant fairly soon afterwards. More severe pain began approximately 2 years later; fast forward to now and I have had 9 more operations involving ablation, done by regular gynaecologists, and a hysterectomy and bilateral salpingo-oophorectomy after endo was found inside my ovaries. I continue to have bowel issues and lower pelvic pain regularly. I requested a referral to a specialist but was denied, even though a private consultation with the specialist suggested residual endometriosis on the bowels and appendix. My local consultant continues to refuse to refer me and I feel totally let down by it all. My life now is near non-existent. I am constantly exhausted and in varying degrees of pain and, as a result of all that's happened, I am also now clinically depressed...I work for the NHS in Wales and, due to sickness absence, I am now on my 2nd formal warning. (NJ, 41)*

The lack of tertiary services in North Wales creates significant inequality in service provision between women in Wales.

The designated endometriosis centre for women in North Wales is in England (i.e., Arrowe Park Hospital, Birkenhead). It has proven difficult to obtain information regarding the numbers making use of this service because the service has not been audited by BCUHB. BCUHB confirmed that 19 cases had been treated in 2017, but it had been difficult to obtain this information. There may be some referrals from BCUHB going to other English centres (e.g., Countess of Chester Hospital) but they appear to be very few in number. There are currently no agreed criteria for referral to

the English centres; it is done on a case-by-case basis, thus leading to variation, inequality and potential harm across Wales. Communication from the endometriosis centre in England to the referring clinician in Wales has been identified as an issue in the past.

For women in the Welsh Borders, the nearest endometriosis centres are also in England (Birmingham and Worcester) and, similarly, there is no specific pathway in place to facilitate referral.

#### **d) Endometriosis specialist nurses**

The recent NICE guideline (<https://www.nice.org.uk/guidance/ng73> (section 1.1.3) now makes clear that **every** woman with suspected / confirmed endometriosis should have access to a specialist nurse practitioner.

Currently, there is only one Endometriosis specialist nurse in Wales and her activity is as part of the BSGE endometriosis centre in Wales (Cardiff). This provision has proved to be insufficient for the care of women with endometriosis in South Wales and is not accessible currently to non-Cardiff and Vale residents. There is no provision of a specialist nurse for north and west of Wales within Wales, as to date these locations do not have endometriosis centres.

The specialist endometriosis nurse plays an important role in disease perception, management, and the provision of specialised care and facilitating appropriate patient pathways. Easy access to a specialist nurse for advice and suggestions as to management has reduced unscheduled admissions for pain control, reducing harm and waste in Cardiff. (E Bruen, Patient Satisfaction audits 201, European Society of Gynaecological E and 2016 presented at BSGE Cornwall, AAGL)

#### **e) Non Gynaecology Medical Specialists: Pelvic pain specialists, paediatric pelvic pain specialists**

Endometriosis is a chronic condition and needs long-term management. It is essential to manage patient expectations and provide access to non-surgical services for those for whom surgery is contraindicated, inappropriate or has failed to resolve their issues.

As evidenced by the Welsh consultants' survey Appendix 2, currently, such services are in short supply, can be difficult to access, have excessive waiting times and are not multidisciplinary (including pain management, psychology, physiotherapy, dietology) in most Welsh hospitals. The Welsh consultant survey indicated that almost half of the respondents were uncertain of the waiting time for pain appointments and 20% of respondents indicating that the wait was more than 7 months.

Pelvic pain is not prioritised and, as such, there is an insufficient cohort trained or available to work in the field. There are general pain clinics in District General Hospitals but not specific Chronic Pelvic Pain clinics.

There is a lack of training for, and recognition of, paediatric pelvic pain.

*In 2013, when I was 13, I fainted in school from horrendous stomach pain. I was taken to A&E where they did blood tests and an ultrasound. A doctor told me that everything looked fine on the scan, so it was nothing to do with gynae. This happened regularly over the 4 years since. I would be rushed to A&E with the same pain and got told it was nothing and that I just needed to learn to deal with period pain. One morning it was so bad that my Mum took me to the GP. He spoke to the local gynaecology department, but they said that it 'couldn't be anything gynae related as I was too young'. Luckily for me, my GP decided to refer me anyway. Nine months later, when I eventually saw the gynaecologist, she told me she was almost certain it was endometriosis. I had a laparoscopy when I was 18 and was diagnosed with endometriosis which was covering my womb. (AA, 18)*

#### f) Allied Professionals **Physiotherapists Psychologists and other**

Pelvic floor physiotherapy has been shown to have real and tangible benefits for women affected by pelvic pain, including endometriosis and post-surgery. However, our assessment of current numbers of pelvic floor physiotherapists in Wales demonstrates a real lack of provision (Appendix 6).

The advantages of making pelvic physiotherapy readily available to pelvic pain patients are not widely known or understood by gynaecologists, GPs and affected women.

Improvements in the provision of healthcare can reduce suffering in endometriosis. However, our mixed methods research shows that women experience a range of psychological and social consequences from the endometriosis that psychological support could help resolve, notwithstanding the resilience women are likely to have developed through support groups and other forms of support. In light of the diversity of issues that emerge for women with endometriosis (e.g., chronic pain, infertility, loss, relational, social occupational challenges) health psychologists with expertise in women's health should be consulted when developing support services for women with endometriosis. Access to health psychologists should also be facilitated when required.

#### g) **Researchers**

There is a lack of significant research projects on endometriosis originating in Wales, with only a small number of basic research projects undertaken. Endometriosis is low research priority for funding schemes, despite it affecting a similar population profile as asthma and / or diabetes.

## 2.2. Summary

The findings reported indicate low expectation of service delivery and health care that impacts on quality of life and well-being.

- There is a lack of NHS Wales information resource for women with potential endometriosis symptoms.
- There is lack of awareness and knowledge of the condition on the part of healthcare professionals.
- There are gaps in training within gynaecology, at all levels, regarding the management of endometriosis.
- There is insufficient capacity at tertiary level across Wales to cope with current and future demand.
- Women for whom surgery is inappropriate or fails to resolve some symptoms require continued input and support, including access to physiotherapy and chronic pain services.
- 

It must be recognised that follow up appointments will be needed and that the need to follow up ratio will differ from that of many gynaecological clinics that do not manage chronic conditions.

It is inappropriate to expect patients from out of area to travel to Cardiff, England (i.e., Arrows Park), or any far-distant tertiary centre, for regular, on-going appointments for pain management / physiotherapy or any other recurrent consultations. The provision of such care closer to home is essential especially given the level of physical impairment and limitations many women experience.

Our research clearly shows that women were active agents in seeking medical attention for their endometriosis in line with the Welsh Government strategy of '*Shared Decision Making*' to take effect, and for patients to be equal partners in their health. However, they are let down by the fragmented care that ensues due to unclear pathways.

### **3) Developing a robust care pathway for the management of safe sustainable high quality and cost-effective endometriosis care, including primary, secondary, and tertiary care, provided in all settings, including remote and rural**

Concurrent with the Task & Finish Group, the National Institute for Health and Clinical Excellence (NICE) produced comprehensive new guidance on endometriosis management. Indeed, the draft guidance was out for consultation during the term of the committee and many members contributed feedback. The finalised guidance was published in September 2017 and is available on line <https://www.nice.org.uk/guidance/ng73>

Review of the NICE guidelines during the group's deliberations has led to suggestions as to how it can be optimised for use in Wales. Accordingly, the Task & Finish group has devised a pathway suited to Wales. The minor amendments to customise the document below are shown in red text.



First presentation

**Suspect endometriosis** (including in young women aged 17 and under) with 1 or more of:

- chronic pelvic pain
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- deep pain during or after sexual intercourse
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- infertility in association with 1 or more of the above.

**Assess women's individual information and support needs**

Take into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs.

**Also:**

- discuss keeping a pain and symptom diary [sign-post to website; resources]
- offer an abdominal and pelvic examination to identify abdominal masses and pelvic signs
- consider an ultrasound scan (see page 2). [Describe what are the signs]
- refer to nurse specialist or specialist counsellor & provide information [Describe links & resources]

Be aware that endometriosis can be a long-term condition and can have a significant physical, sexual, psychological and social impact. Women may have complex needs and may require long-term support.

Initial management

**Offer initial management with:**

- a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination [unless self appropriately administered previously], and
- hormonal treatment combined contraceptive pill (may be taken continuously for six months) or a progestogen (preferably desogestrol)
- refer to the NICE guideline on neuropathic pain for treatment with neuromodulators.

If fertility is a priority, the management of endometriosis-related subfertility should have multidisciplinary team involvement with input from a fertility specialist. This should include recommended diagnostic fertility tests or preoperative tests and other recommended fertility treatments such as assisted reproduction.

Also see **Fertility is a priority** on page 2.

**Consider referral to a gynaecology, paediatric & adolescent gynaecology, or specialist endometriosis service (endometriosis centre) if:**

- a trial of paracetamol or NSAID (alone or in combination) does not provide adequate pain relief **AND**
- initial hormonal treatment for endometriosis is not effective, not tolerated or is contraindicated.
- symptoms recur following surgical treatment

Referral

**Consider referral to a gynaecology service or consultant with special interest in endometriosis**

- for severe, persistent or recurrent symptoms of endometriosis
- for pelvic signs of endometriosis, or
- if initial management is not effective, not tolerated or is contraindicated.

**Refer women to a specialist endometriosis service (endometriosis centre) if they have suspected or confirmed deep endometriosis involving the bowel, bladder or ureter.**

**Consider referring young women (aged 17 and under) to a paediatric & adolescent gynaecology service, gynaecology service or specialist endometriosis service (endometriosis centre), depending on local service provision.**

Do not use pelvic MRI or CA-125 to diagnose endometriosis.

**Consider transvaginal ultrasound:**

- to investigate suspected endometriosis even if pelvic and/or abdominal examinations are normal
- for endometriomas and deep endometriosis involving the bowel, bladder or ureter.

Consider a transabdominal ultrasound scan of the pelvis if a transvaginal scan is not appropriate.

Do not exclude the possibility of endometriosis if the abdominal and/or pelvic examinations or ultrasound or MRI are normal.

Consider referral for assessment & investigation if clinical suspicion remains or symptoms persist.

Consider laparoscopy to diagnose endometriosis, even if the ultrasound was normal.

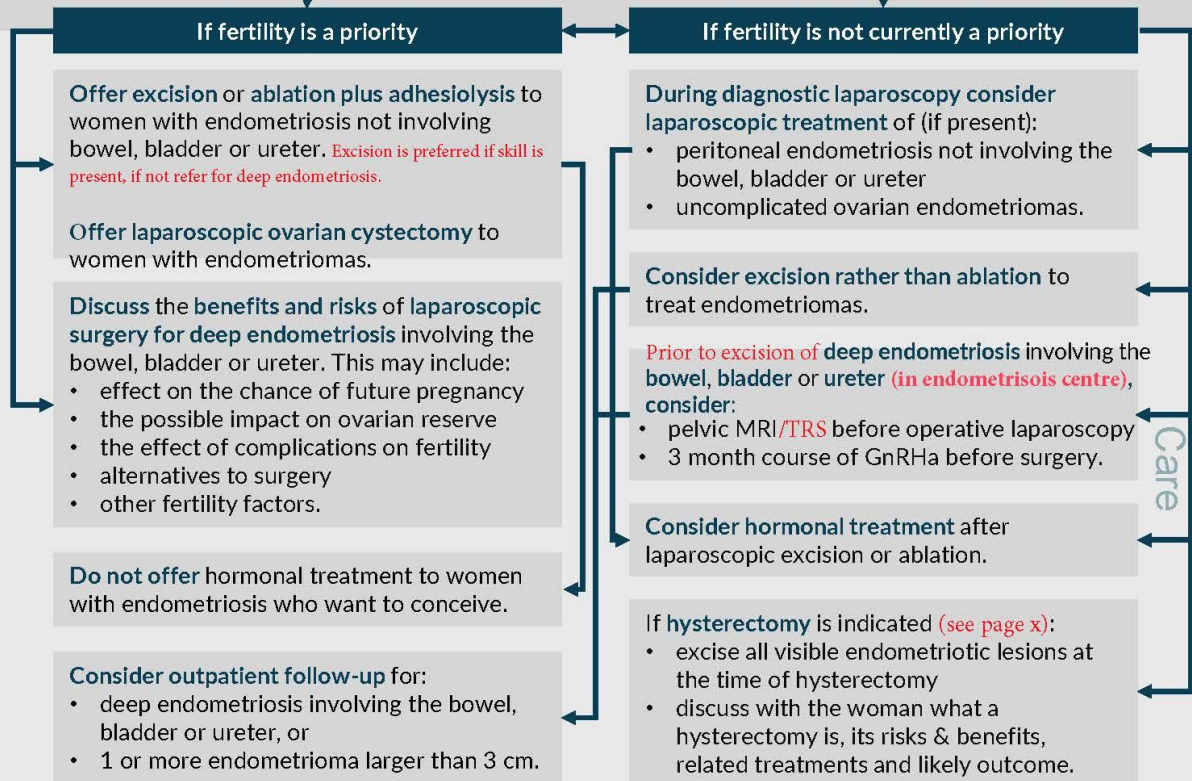
**Discuss surgical management options** with women with suspected/confirmed endometriosis:

- what laparoscopy involves, and that it may include surgical treatment (with prior patient consent)
- how laparoscopic surgery could affect endometriosis symptoms
- the possible benefits and risks of laparoscopic surgery
- the possible need for further surgery, including the possible need for further planned surgery for deep endometriosis involving the bowel, bladder or ureter.

During diagnostic laparoscopy, a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis.

If a full systematic laparoscopy is performed and is normal, explain to the woman that she does not have endometriosis and offer alternative management. (hormonal, pain

Diagnosis



**2 Endometriosis: diagnosis and management NG73**

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### 3.1 Education / schools / Public Health Wales

- *School education programmes* (starting at primary level) should inform children, in an age appropriate way, of what might constitute typical menstrual pain and bleeding and make aware of the early signs of pelvic pain, dysmenorrhea, abnormal menstrual bleed. Equally, teachers need information on methods of empowering girls to talk about menstrual problems, if encountered, to their parents and GPs. This information and advice should be included in the curriculum so that all children receive this education. Boys too could benefit from the information about menstrual health to reduce a culture of normalising signs and symptoms of disease. Information needs to be delivered in a planned and managed way by trained educators; we do not want to scare girls (or boys) about periods.

All schools and colleges need to have a confirmed pathway in place for girls to access the 'right person at the right time' to discuss issues of this nature. Estyn should be assessing this provision as part of its inspections related to health / well-being.

School nurses, whilst not routinely available, should also be trained in symptom recognition and sign-posting.

- *Further and Higher Education* (University/ colleges/ training programmes / personal tutors / student union welfare officers and staff) should be able to signpost appropriately because symptoms can impact on course completion, resulting in early dropout rate. This can have negative consequences for future employability and earning potential.
- *Well Women Workplace Programmes* should be implemented where possible to address absenteeism, low concentration, and low productivity in women that suffer with endometriosis. Increased awareness is required amongst Occupational Health providers and advisory services.
- *Community education* through GP practices and Well Woman / Sexual Health Clinics to encourage women and their families to advocate for appropriate care. A public health campaign, led by Public Health Wales, should be devised to take the 'normal' out of the endometriosis. Public Health Wales should be involved in raising awareness of endometriosis by utilising patient co-produced video, leaflets, and social media.
- Non-NHS resources, for example, Endometriosis UK, Support Groups and FTWW for patients in Wales specifically, and the website as described in section 3.2, should be routinely sign-posted to girls and women affected.



## **We recommend the following:**

*Knowledge of menstrual health must be embedded within the education service, and resources must be developed to support this for the whole of Wales. An Implementation Group, with core representation from the Task & Finish Group, should be put in place to co-produce strategy and materials. It may be appropriate to enlist the assistance of our medical students.*

*Advisory agencies and Occupational Health services must recognise that endometriosis is covered under the Disability Section of the Equality Act 2010, and support women accordingly. Welsh Government to endorse this message and ensure adequate training.*

*Public Health Wales to develop and deliver a public education programme similar to the FAST programme for stroke awareness with the Implementation Group's support.*

## **3.2. Information Technology**

### **3.2.1 Web resource**

Online information for patients, symptom questionnaires, pain and menstrual diaries should be available via a NHS hosted website. The option for a patient to request that this information should be available to her GP, and subsequently, secondary and tertiary care, should be provided. This means the structured history is input once, and pain diaries can be updated and visible to clinicians as the patient progresses through treatment.

Such new initiatives would build on work within the NHS Wales Informatics Service (NWIS). The NWIS are designing and developing systems and services to support the Welsh Government's 'Informed Health and Care' strategy which presents the Digital Health and Social Care Strategy for Wales. Our recommended initiatives, if funded, would augment the digital services being implemented within two of the strategy's work-streams:

Firstly, the *Information for You* work-stream, aims to enable people to connect with health and social care in increasingly more effective ways to support their needs, including access to their own records and being able to record information about themselves and their care.

Secondly, the *Supporting Professionals* work-stream aims to improve access to information for those providing care through a common core set of systems and information services that will be available consistently across the whole of Wales, regardless of organisation.

Within the *Information for You* work-stream we aim to establish access to internet facing web content, that will include functionality to allow women to record structured data associated with their symptoms through electronic forms and diaries.

These initiatives will:

- (a) 'sign-post' a woman into primary care based on applying an algorithm to the answers given to the questions recorded on the form and
- (b) allow a woman to record a diary of her condition.

Both will be share-able with clinicians in primary and secondary care, should consent be given, achieved by using the standard integration services to load into the NHS Wales Electronic Health Record.

### 3.2.2. **Image storage and transfer**

Once the service is in place, it should be compulsory that images taken at diagnostic laparoscopy be uploaded to the patient's clinical record in order that high quality images are retained and available for clinical teams in secondary and tertiary care, and ideally available for patient viewing subsequently on her online personal health record.

Access to the data and documents by clinicians will be enabled via use of the Welsh Clinical Portal (WCP). This approach and these same set of services are those that have been developed for the PREMS/PROMS initiatives that are being managed within the *Information for You* work-stream.

Within the *Supporting Professionals* work-stream, clinicians will have access to a wide array of additional patient data and clinical information that is already being stored in the Electronic Health Record and once again, accessed through the WCP.

This includes an All Wales perspective on diagnostic results and reports from Radiology (including access to images) and Pathology services, along with clinical summaries, clinical notes and letters. We will aim to add to the content of the record through this initiative by further integrating the electronic record with systems that provide clinical information from other relevant systems too, including summaries and imaging from Laparoscopy systems. These data will then become available for clinicians again via the WCP. Services that enable clinical letters and summaries to be sent electronically to GPs will also be provided.

Finally, we will aim to build on work already under way with other clinical networks that aim to resolve cross border information flows. These are resolving the need for integration into and out of clinical services in England, and aim to allow diagnostic and imaging data to flow between the two healthcare systems along with referrals clinical letters and summaries.

The use of electronic patient records minimising data entry duplication must be a medium-term objective to facilitate care and communication across NHS Wales, reducing variation and potential harm.

## **We recommend the following:**

*NWIS should work with the Implementation Group to develop online resources for patients and clinicians, including awareness tools, symptom recognition & tracking, and patient pathway(s). Welsh Government should support the allocation of NWIS resource to this endeavour.*

*NWIS, Welsh Government and Health Boards should facilitate the storage of laparoscopic images within the All Wales Electronic patient record such that they are available across the health network and ideally for patients in the future.*

### **3.3 Primary Care: GPs and Practice Nurses**

- It is vital that the NHS Direct resource is modified in line with the recent NICE guidance.
- GP education on endometriosis should be enhanced through seminars, case presentations, and updates on endometriosis treatment and management. GP champions per practice or cluster, who might attend the local DGHs specialist clinics, should be identified. In addition to GPs with a specialist interest in Women's Health to mentor training should be identified.
- The importance of endometriosis must be emphasised to GP trainees during their obstetrics and gynaecology rotation. Postgraduate Deans should be able to audit this.
- The RCGP is working in partnership with Endometriosis UK to develop a toolkit and online educational resource on menstrual wellbeing and prompt referral to secondary care where appropriate. When this resource is available it should be discussed within the implementation group in light of planned changes to Welsh educational curriculum, adapted for Wales, where possible, and its implementation audited.
- GPs must be involved in generating local managed care pathways for the referral and treatment of endometriosis as per NICE guidance.
- Practice nurses must be aware of the symptoms of endometriosis and be able to signpost and advise accordingly. The education of practice nurses should form part of the remit of the local endometriosis nurse specialist's role.
- GPs must be confident to prescribe HRT to oophorectomised women with endometriosis under guidance from secondary care.
- Patient involvement is a key part of training and needs to be consistent across Wales, both in terms of symptom awareness, and communication / listening

skills: 'Nothing about us, without us'.

- Paediatricians can be 'first responders' in young girls presenting with pelvic pain; they need to have access to diagnostic tools and an easy referral pathway to gynaecology. School nurses are often a first port of call.
- Primary care should have direct access to resources such as psychological support, pelvic physiotherapy and pelvic pain management to assist women with a known, prior or suspected diagnosis of endometriosis.

### **We recommend 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.*

## **3.4 Secondary Care gynaecology**

### **3.4.1 Education of Gynaecologists**

Knowledge of endometriosis varies amongst general gynaecologists as well as primary care doctors.

All gynaecologists must be able to diagnose and initiate the management of endometriosis, but local consultants with a special interest will be responsible for ensuring consistency and quality within each unit.

Only gynaecologists with skills in minimal access gynaecology, and training in the recognition and excision of non-complex endometriosis should undertake surgical

procedures (see section 3.4.3). This level of expertise would ensure the patients have initial surgery performed by a clinician with the expertise to excise disease, and would allow the specialist clinician to develop experience and skill over time.

If the clinician has a patient with complex disease, the patient should be referred to a BSGE tertiary endometriosis centre for further surgical excision. Further developments should be planned for multicentre multi-disciplinary meetings in the future to discuss cross Health Board referrals throughout Wales.

The number of places for the advanced laparoscopic surgery training programme is limited and should, at a minimum, continue to train one candidate a year in Wales for the foreseeable future to aid in generating the consultants with endometriosis special interests required for each Health Board.

### **3.4.2 Ultrasound training for gynaecologists, radiographers and radiologists**

Ultrasound is a dynamic investigation that needs to be interpreted in real-time within the clinical context. Pain mapping and the mobility of the pelvic organs are essential parts of the investigation for women with pelvic pain. The British Society for Gynaecological Imaging BSGI and the BSGE are working together to improve imaging in endometriosis.

Local Health Boards (Radiology and Gynaecology Departments) should ensure that scans are undertaken emphasising the following points:

- Undertake a structured examination of the pelvis and standardised report format
- Identify diagnostic strengths of US such as perception of pain; normal or abnormal location of uterus and ovaries; endometriomas; rectovaginal assessment
- Identify trained gynaecologists and/or sonographers with expertise in pelvic scanning and clinical mapping of endometriosis to undertake imaging when the request emphasises pelvic pain

### **3.4.3 Standardisation of diagnostic laparoscopy**

It is essential that gynaecologists are trained to recognise multiple visual presentations of disease, subtle changes, and to appreciate that adhesions can often obscure the extent of the disease.

There needs to be a minimum accepted standard for patients undergoing a diagnostic laparoscopy in Wales. Developing standards in Wales should drive future standard setting for the whole of the UK

Every gynaecologist performing the operation needs clear photographic evidence of all areas checked during the procedure. As a minimum, the procedure should have information regarding the following sites:

Abdomen: both left and right hemi-diaphragms; anterior liver surface; both anterior abdominal walls and note if the bowel is adherent or the appendix affected.

Pelvis: utero-vesical fold; broad ligaments including round ligaments; whole surface of ovaries; ovarian fossae; both pelvic side walls; utero-sacral ligaments; para-rectal spaces; pouch of Douglas (with use of rectal probe to ensure complete analysis of POD); anterior rectum.

If views are not obtained along with photographic evidence then this is deemed inadequate laparoscopy.

Photographs should be used to explain how extensive disease is but also, in cases where no disease is seen, explanation of this is required and to possibly look at other causes of pathology. Example photograph set attached (Appendix 8)

For referrals to the endometriosis centres, the above photographic views need to be incorporated in referral notes as these will assist in determining length and resource needed for further surgical planning to ensure the appropriateness of the surgical procedure undertaken.

Currently small photographic prints, often in black and white, are all that are available, and these are often unsatisfactory. Electronic storage and access must be a future objective, as discussed in 3.2.2.

### **We recommend the following:**

*Secondary care must be involved in implementing the recent NICE guidance strengthening the care pathways for women.*

*Local Health Boards should ensure that imaging for women suspected of endometriosis is undertaken and / or overseen by practitioners with special interest in pelvic pain.*

*An Endometriosis Lead for each Health Board must be appointed to ensure high standards of disease recognition, diagnosis, and treatment.*

*Welsh Government, via local Health Boards, the postgraduate Deanery and the RCOG should work to ensure standard of laparoscopy and image storage are raised.*

*Trainees and consultants must be trained to excise the disease where possible and must refer on if such skills are not available.*

*The pathway for onward referral to tertiary care needs to be clearly mapped and adequately resourced. Women and healthcare professionals should be aware of how to access it.*

*Health Boards and Obstetrics & Gynaecology departments must recognise that endometriosis is a chronic condition and that symptoms may recur, potentially requiring an increased number of follow ups.*

*A specialist endometriosis nurse should be appointed immediately for every Health Board with a view to availability in every department where women with endometriosis are cared for, in the short term. . Funding should reflect the complexity and skill set required for this extended nursing role which may cover more than one site, and will include education of colleagues in primary care*

*There is only one endometriosis specialist nurse in Wales. Her expertise must be utilised to train other specialist endometriosis nurses.*

### **3.5 Tertiary care – BSGE Endometriosis Centres**

Tertiary care is provided in BSGE recognised endometriosis centres in Cardiff for South Wales and at Arrows Park Hospital, Birkenhead for North Wales. Patients in central Welsh borders have no designated centre but may be referred to Worcester, Wolverhampton, or Birmingham. There is no clarity or consistency as to whether an Individual Patient Funding Request (IPFR) is required or not.

For all of Wales the resourcing of tertiary endometriosis care is inadequate and unsustainable, both in terms of the capacity and the resources allocated to provide it. Welsh Government and Health Boards must resolve this issue ideally by commissioning tertiary complex services via separate funding through the Welsh Health Specialist Services Committee (WHSSC).

Patients are prepared to travel for their surgery and clinics could be delivered locally. Our patient survey data indicates that there may be significant unmet need.

#### **3.5.1 South Wales**

The current funding arrangements for resourcing tertiary endometriosis at the BSGE centre in Cardiff are unsustainable and Welsh Government should urgently consider the following options:

- Commission tertiary endometriosis centres activity via Welsh Health Specialist Services
- Provide a block grant to C&VUHB to recognise the deficiency in resource allocation.
- Facilitate a tariff uplift between Health Boards so that complexity is recognised and additional funding follows the complex patient. A similar model currently exists for gynaecological cancer patients from Newport.

- To increase capacity for tertiary endometriosis care in South Wales, Welsh Government should appraise the following options and work with Health Boards to achieve a solution:
  1. Expand the capacity at UHW (difficult due to insufficient theatre space and time)
  2. Create more BSGE recognised endometriosis centres (whilst there is one surgeon in Newport and at least another in Swansea and Bridgend, there are many hurdles to achieve Centre status. The option of seeking endometriosis specialists to appoint as new consultants is feasible, but much easier to attract them to an established centre).
  3. Establish a virtual South Wales Endometriosis Centre over the three sites. Cardiff to provide support and mentoring to enable the gynaecologists in Swansea and Newport to tackle the intermediate cases with only the very complex being operated on in Cardiff. This would also require a video linked MDT meeting.
  4. Establish the South Wales Endometriosis Centre at a new location, for example, Royal Glamorgan or Bridgend. This option has the advantage of releasing pressure on limited theatre capacity at UHW which has been designated to accommodate the major trauma centre for South Wales. Endometriosis clinics could be held both at the Centre and locally by specialists involved in the service. Surgeons employed by the three Health Boards could operate in the Centre with support from the existing accredited consultants and colorectal surgeons. Consultants would maintain part of their practice at their existing institutions.

The consensus amongst the Task and Finish group would be to endorse options 3 and 4 with an immediate support of option 3, working towards option 4 within 1 – 2 years.

The British Society for Gynaecological Endoscopy executive has indicated that a Centre based over more than one hospital site is acceptable, provided the standards are universally applied.

### 3.5.2 North Wales

The referral pathways for patients to tertiary BSGE endometriosis centres in England at the Wirral's Arrowe Park, Liverpool Women's (or Alder Hay for paediatric patients) and Chester need to be clarified and strengthened.

Funding currently provided by BCUHB on an individual patient basis must be formalised and funded in a similar manner to the options discussed for South Wales. It should not be the patient's responsibility to find out about the centres and make a case for referral accordingly.

All clinicians involved in patient care need to know of – and use – the pathways in place, recognise their own limitations, and be willing to refer on appropriately. This



includes both local gynaecologists, GPs and appointed specialist nurse(s). Ideally, there would be a centralised resource or point of contact accessible to clinicians and patients that lists all contracted tertiary endometriosis-specific centres and pathways.

Women with complex endometriosis should be audited with endometriosis leads at each hospital site adhering to the referral criteria as specified in the recent NICE guidance <https://www.nice.org.uk/guidance/ng7> would enable quantification of the demand for tertiary endometriosis services and for BCUHB to evaluate whether a North Wales Endometriosis Centre would be a viable option, possibly linking with a local English Centre e.g. Arrowe Park.

### **3.5.3. Welsh Borders**

Our research shows that no formal referral pathway to a tertiary endometriosis centre exists in the Welsh Borders, and no clarity on the English centres that should receive referrals. This lack of pathway has resulted in patients sent many miles for appropriate care in Cardiff or England and, in some cases, provided with suboptimal care in non-specialised hospitals closer to home. The system in Wales does not allow for general hospitals in England to refer complex Welsh patients appropriately themselves, resulting in long delays in treatment, variability and harm.

The pathway for referral to tertiary care should be facilitated without re-referral to Wales, and hospitals on the Welsh Borders should be empowered to make an appropriate and justified onward referral to a BSGE Endometriosis Centre in line with patient-centred and prudent healthcare principles.

### **3.5.4 Links between tertiary endometriosis centres and assisted conception**

The link between tertiary endometriosis centres and assisted conception is suboptimal.

Given that complete excision of endometriosis can improve medically assisted and unassisted pregnancy rates, it makes clinical and economic sense to excise disease prior to commencing interventions with assisted reproductive technologies (ART). However, the current referral pathway may mean that some women only discover endometriosis at the time of referral to fertility clinics. For example, GPs directly refer to the Wales Fertility Institute (WFI) without secondary care gynaecology being involved. This has led to a number of women discovering that they had endometriosis at the same time they were seeking intervention to resolve infertility. Such women will have already waited a considerable time for their fertility treatment. A new referral to secondary care or the BSGE endometriosis centre for surgical management of endometriosis at this time would start a new WG pathway with a 36 weeks Referral To Treatment (RTT) target. This referral for endometriosis would create considerable delay and could take patients outside of the Welsh agreed age criteria, making them ineligible for NHS fertility care.

Solutions are possible, but currently not part of a formal pathway. Following the appointment of a new Director of WFI in 2017 criteria have been agreed between WFI and the BSGE endometriosis centre to manage women with complex fertility and endometriosis needs along a combined pathway such that the WFI is aware of the women before their surgery so as to optimise their chances of successful pregnancy, In addition, there have been special dispensations enabled for women with endometriosis who have a particular threat to their ovarian reserve such that they can follow an accelerated pathway. Due to these agreements and the adoption of strict selection criteria for IVF, the waiting time for assisted conception has been dramatically reduced for women with endometriosis, and the success rates increased considerably (evidence?).

Similar issues affect women from North Wales and Borders as ART can be given in units that do not necessarily provide tertiary endometriosis care (e.g., Shrewsbury, England). Alternatively, referral could be made to English hospitals that can provide ART linked to endometriosis tertiary care but such hospitals may not be the preferred provider for BCUHB (e.g., Liverpool Women's Hospital) causing the need for a prior referral for surgery to another hospital, which is time consuming, costly, and ineffective.

Pathways linking assisted conception and tertiary endometriosis that enable management of such women at one centre must be facilitated.

### **We recommend the following:**

*Referral pathways to tertiary care for all of Wales must be clarified and enforced as a matter of urgency and the information be available for clinicians and patients.*

*Tertiary care capacity must be increased and adequately resourced see option appraisal in 3.5.*

*A clear pathway and a regular Multi-Disciplinary Team meeting, to include representatives from tertiary fertility and endometriosis centres, must be established in order to discuss and prioritise those complex women with fertility and severe endometriosis.*

*Within the Cardiff endometriosis centre the associated services including colorectal, urology and rectal endoscopic scanning are formally resourced and contracted with succession planning if individuals are absent.*

### **3.6 Pelvic Pain Management and Physiotherapy**

From the evidence in Appendix 9, it is clear that early assessment and management of pelvic pain is an essential aspect of caring for women with endometriosis. There should be an endometriosis Nurse Practitioner overseeing basic pain management. The local pain clinic has a role to play and has to be multidisciplinary, providing a biopsychosocial approach to chronic pain management.

All women and adolescents with endometriosis should have access to the above services to prevent central sensitisation resulting in the progression of pain area and intensity as well as involving pain in other pelvic organs, including the abdominal wall, the back, and other locations.

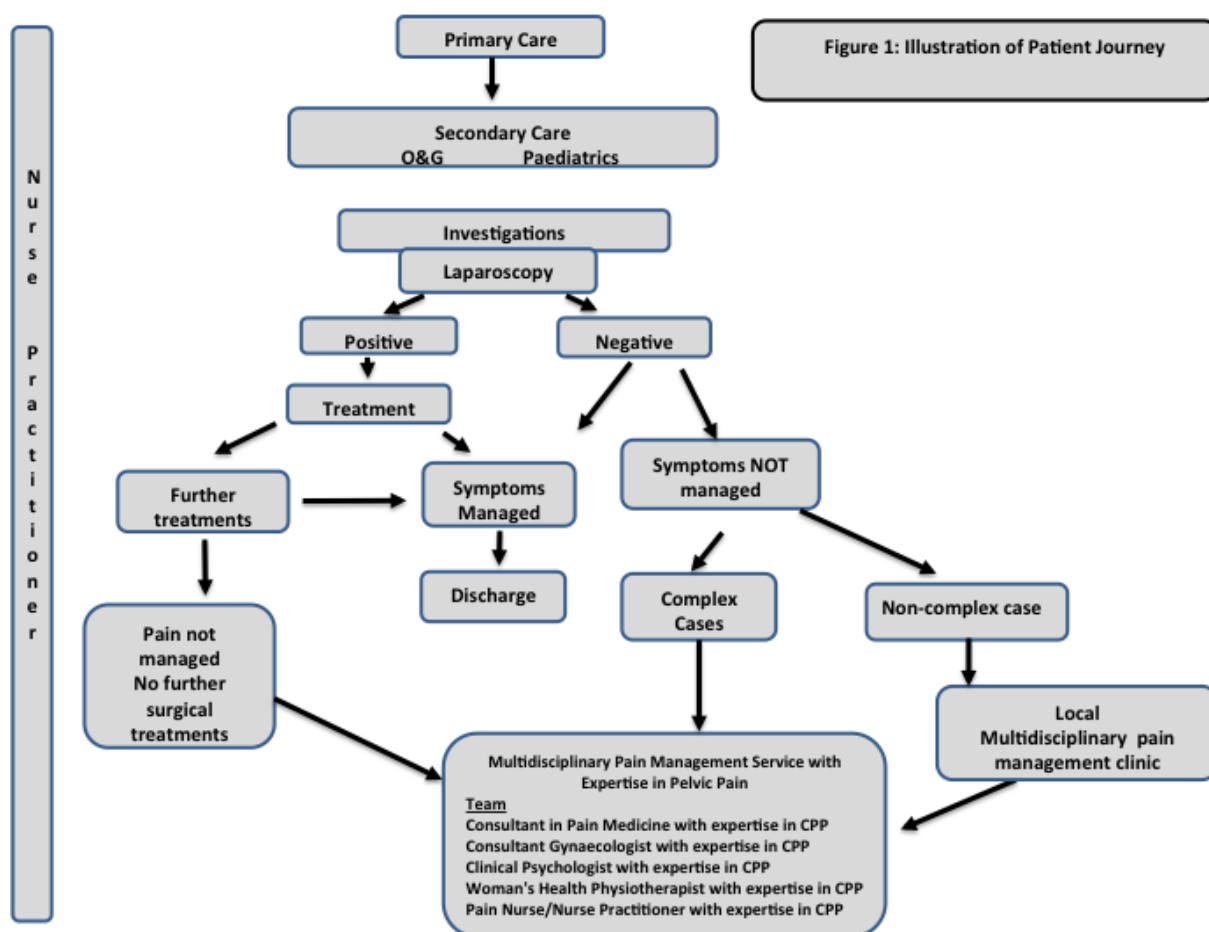
Failure to manage the pain appropriately carries the potential risk of developing chronic Pelvic Pain Syndrome with symptoms of widespread pain, sleep disturbance, psychological, emotional, as well as functional impairment. This confers a substantial burden on individuals, employers, healthcare systems and society in general (Brevik et al 2009). Further information is provided in Appendix 9.

It is prudent that more complex cases have timely access to Chronic Pelvic Pain Multidisciplinary Clinics with expertise in pelvic pain assessment and management (CPP MDT Clinic). Such expert clinics can either be accessed by tertiary referral system between health boards in Wales or sit within a specialised centralised endometriosis service. Wales' geography mandates a CPP MDT Clinic for North, Mid and South of Wales. There is already CPP MDT clinic at Aneurin Bevan University Health Board which has been operating since 2004.

The pathway described in Table 1 sheds further light on recommended pain management provision for endometriosis patients in line with NICE guidance. It also explains the recommended personnel and available management modalities in the CPP MDT clinic.

A multidisciplinary approach to chronic pelvic pain management is required from onset rather than after surgical intervention or when standard medical management has failed to improve or resolve symptoms (O'Donovan 2017). This MDT approach from initial diagnosis would provide access to specialists in chronic pelvic pain management, physiotherapists, dieticians, psychologists; CBT; coping strategies; counselling, and lifestyle measures.

## Composition and tasks of Multidisciplinary Pain Management Service



### Multidisciplinary Pain Management Service

#### Team Members with Expertise in Chronic Pelvic Pain (CPP)

Consultant in Pain Medicine with expertise in Pelvic Pain  
 Consultant Gynaecologist with expertise in Endometriosis  
 Clinical Psychologist  
 Women's Physiotherapist  
 Pain Clinical Nurse Specialist (CNS) / or Endometriosis Nurse

#### Modalities of Management / Treatment (not exhaustive list)

1. Biopsychosocial approach
2. Functional restoration
3. Detailed assessment of pain and organs involved as pain generators
4. Multimodal management approach to multifactorial pain generators
5. Optimisation of pharmacotherapy
6. Pain management various nerve blocks.

7. Posterior Tibial nerve stimulation
8. Detailed psychological assessment and therapy including mindfulness, acceptance, coping strategies, pain management principles, Eye Movement Desensitisation and Reprocessing (EMDR), pelvic pain specific pain management programme, etc.
9. Physiotherapy including pelvic floor
10. Pain CNS support, explanation and help with implementation of management plans
11. Complimentary Therapy
12. (Please note the treatment combination depends on identified pain generators and emotional impact of pain. Not every patient will require all these treatments).

### **We recommend the following:**

*Pelvic pain management and support must be integrated into the early assessment of women suffering from endometriosis. This can ideally be undertaken by an endometriosis nurse practitioner.*

*Pelvic floor physiotherapy forms an integral part of CPP management, and physiotherapists with training in CPP should be accessed within secondary care. This will require training of physiotherapists in CPP management.*

*Tertiary endometriosis services in North and South Wales should have access to a multidisciplinary CPP management service with gynaecologists, anaesthetists, psychologists, physiotherapists, and dietetic input. This should be a rapid access service triaged via the endometriosis nurse practitioner. Options for women from Mid-wales must be facilitated.*

## **4 Outcome measures -**

### **4.1 Quality standards as per NICE consultation February 2018**

Subsequent to the publication of NICE guidance on the management of endometriosis September 2017 <https://www.nice.org.uk/guidance/ng73> , a draft consultation on outcome measures is currently taking place, aspects of which are briefly summarised below. The NICE document is likely to be finalised by July 2018 and we strongly urge that these outcome measures are adopted in Wales, as follows:

*4.1.1 "Women presenting with suspected endometriosis have an abdominal and pelvic examination."*

Auditable standards - Evidence of protocols detailing symptoms of endometriosis and the need for abdominal and pelvic examination when this is suspected. The data source would be local data collection, for example local clinical protocols. Data on women presenting with endometriosis symptoms such as painful periods or painful intercourse, women with a working diagnosis of endometriosis, or all women presenting with these symptoms would need to be collected. The proposed website (see Section 3.2.1) could also be a source for this information as might information systems in primary care.

*4.1.2 "Women receiving initial hormonal treatment for endometriosis are referred to a gynaecologist if it is not effective, not tolerated (unwanted) or contraindicated"*

This quality standard is expected to contribute to improvements in the following outcomes:

- rates of early diagnosis of endometriosis
- quality of life of women with endometriosis
- access to specialist services for management of endometriosis
- pain management for women with endometriosis (Note - We interpret this statement as dedicated pelvic pain management).

*4.1.3 "Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service." (or who have failed other treatment options)*

This standard monitors access to BSGE endometriosis centres. It should also monitor compliance with RTT targets. We will need a register of all cases of endometriosis to monitor whether the service complies with this standard.

*4.1.4. "Community services are part of a managed clinical network providing coordinated care for women with suspected or confirmed endometriosis".*

#### Structure

- a) Evidence that a managed clinical network for endometriosis that includes community services is in place. Data source: Local data collection, for example local commissioning arrangements.
- b) Evidence that local services within the managed clinical network have agreed clinical and referral protocols for women with suspected or confirmed endometriosis. Data source: Local data collection, for example clinical and referral protocols and pathways.
- c) Evidence that community services know how to refer women with endometriosis within the managed clinical network. Data source: Local data collection, for example referral protocols and pathways.

#### Auditable Outcomes

- a) Number of days lost at school and work because of symptoms of endometriosis. Data source: Local data collection, for example school attendance levels and employment sickness rates. (Might include those claiming sickness / disability benefits as a result of symptoms). This NICE Guidance point reinforces the need to promote the education of young girls and women as to what is tolerable in terms of period pain.
- b) Satisfaction of women with endometriosis with the support they receive. Data source: Local data collection, for example surveys of women with endometriosis. (It is vital that patient experience drives the system).
- c) Number of women who feel able to manage their symptoms of endometriosis. Data source: Local data collection, for example surveys of women with endometriosis.

#### 4.2. Numbers of women added to BSGE database and their follow up

This monitoring should increase as the data collection becomes more robust. The follow up has not been good and must improve. The follow up rates should be reportable to WG and supported in any public awareness campaign. Clerical support should be available to support the email follow up service.

The endometriosis database should be used for non-rectovaginal cases including less complex surgeries and urology operations. This extension to the database must be explored with the BSGE and the option of generating a similar parallel dataset investigated. The questionnaire used by the BSGE includes a Quality of Life assessment and its use should be extended to all women with endometriosis in all clinical settings.

#### **We recommend the following:**

*The NICE quality indicators when finalised in July 2018 should be adopted in Wales.*

*All Health Boards should monitor women with endometriosis either through existing datasets or via a register to facilitate audit.*

*The number of women added to the BSGE database should be reported to Welsh Government as a quality standard.*

#### **5. Research.**

Wales can become one of the important sources of well-designed national studies in endometriosis. Diverse organisations have indicated what could be research priorities (e.g., NICE, James Lind Alliance) and it should be investigated which are aligned with priorities in Wales. To that end the implementation group with relevant consultation should take a strategic view of research priorities. At this time, our research suggests that in Wales the more urgent research priorities would be to carry out:

- Epidemiological studies investigating the prevalence of endometriosis and medical help-seeking for endometriosis in Wales. A priority outcome would be the impact of endometriosis on the health system and individuals.
- Research in early prevention and diagnosis, and interventions addressing (as a priority) the young population.
  - Development and evaluation of school educational resources for menstrual health
  - Development of symptom awareness tools for young women
- Research across collaborative disciplines in the new multidisciplinary setting proposed for the management of endometriosis. A priority would be investigating the causes of diagnostic delay, which is significantly longer in Wales than other UK sites.

- Multidisciplinary approach to research from biomarker/biological studies to translational and clinical application of new diagnostic and therapeutic methods.

This research would assist in targeting resources according to unmet needs in Wales

### **We recommend the following:**

*Work with Health and Care Research Wales and the Universities to prioritise funding research on the epidemiology and early detection of endometriosis in Wales.*

## **6. Recommendations.**

Stakeholders must accept that endometriosis is a condition with significant long-term implications in women's health and therefore needs to be introduced in the list of priorities (Policies, Strategies etc.). This proposal is aligned with the Welsh Government strategic priorities as stated in Well-being for Future Generations legislature and (by implication) its Adverse Childhood Experiences (ACEs) strategy. Women's (and thereby mother's) health and well-being plays a vital role in supporting health and healthy family's initiatives. It is incredibly important that girls' early menstrual health is prioritised to prevent long periods of suffering and stop the on-going cycle of delayed diagnosis, intractable health problems and costs to the economy.

**This review is based on in-depth discussions among a multidisciplinary team of clinicians, academics and patient groups over the past year. The Advisory Group has considered many sources of data, including recent NICE guidelines and extant research as well as produced research in Wales specifically for this Task & Review group. The evidence provided indicates that endometriosis leads to long periods of suffering for the 10% of women affected in Wales. The current provision of services is suboptimal incurring significant and unnecessary costs to the Welsh healthcare system through long delays in diagnosis, repeated ineffective or misinformed treatments, and fragmented care pathways that produce inequality and inefficiencies in care across Wales. These inefficiencies are frustrating for women, and cause poor quality of life that reduces their capacity to lead productive, energetic and happy lives. We strongly urge the Welsh Government and Health Boards to act on the recommendations herein. Endometriosis is a global health priority that cannot be ignored in Wales.**

An All-Wales Implementation Group, with core representation from the Task & Finish Group, should be put in place to ensure that these recommendations are actioned, according to the priorities of the Welsh Government.

### **EDUCATION**

Knowledge of menstrual health must be embedded within the education service, and resources must be developed to support this for the whole of Wales. An



Implementation Group, with core representation from the Task & Finish Group, should be put in place to co-produce strategy and materials.

Advisory agencies and Occupational Health services must recognise that endometriosis is covered under the Disability Section of the Equality Act 2010, and support women accordingly. Welsh Government to endorse this message and ensure adequate training.

Public Health Wales to develop and deliver a public education programme similar to the FAST programme for stroke awareness with the Implementation Group's support.

## **INFORMATION TECHNOLOGY**

NWIS should work with the Implementation Group to develop online resources for patients and clinicians, including awareness tools, symptom recognition & tracking, and patient pathway(s). Welsh Government should support the allocation of NWIS resource to this endeavour.

NWIS, Welsh Government and Health Boards should facilitate the storage of laparoscopic images within the All Wales Electronic patient record such that they are available across the health network and ideally for patients in the future.

## **PRIMARY CARE**

Endometriosis needs to be made a priority for both training of GPs and on-going continuing professional development (CPD). Implementation group to facilitate.

Primary care must be involved in implementing the NICE guidance on endometriosis and local pathway development. (ref 3.3)

(Recommend use of community navigators in primary care settings to signpost patients to appropriate local support groups / services)

Each Health Board will be responsible for 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 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. Services of this nature are of the sort which 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.

*\*Whilst we acknowledge that other Task and Finish groups covering women's health issues are shortly due to report and may recommend community-based pelvic floor physiotherapy services, pelvic pain is a distinct entity and should be treated as such. If such community services were established the advisability of encompassing pelvic pain would need to be assessed. This could form part of the remit of an implementation group*

## **SECONDARY CARE**

Secondary care must be involved in implementing the recent NICE guidance strengthening the care pathways for women.

Local Health Boards should ensure that imaging for women suspected of endometriosis is undertaken and / or overseen by practitioners with special interest in pelvic pain.

An Endometriosis Lead for each Health Board must be appointed to ensure high standards of disease recognition, diagnosis, and treatment.

Welsh Government, via local health Boards, the postgraduate Deanery and the RCOG should work to ensure standard of laparoscopy and image storage are raised. Trainees and consultants must be empowered to excise the disease where possible and refer on if such skills are not available.

The pathway for onward referral to tertiary care needs to be clearly mapped and adequately resourced. Women and healthcare professionals should be aware of how to access it.

Health Boards and Obstetrics & Gynaecology departments must recognise that endometriosis is a chronic condition and that symptoms may recur, potentially requiring an increased number of follow ups.

A specialist endometriosis nurse should be available in every department where women with endometriosis are cared for, and the role extended to include education of colleagues in primary care.

There is only endometriosis specialist nurse in Wales. Her expertise must be utilised to train other specialist endometriosis nurses.

## **TERTIARY CARE**

Referral pathways to tertiary care for all of Wales must be clarified and enforced as a matter of urgency and the information be available for clinicians and patients.

Tertiary care capacity must be increased and adequately resourced, see option appraisal in 3.5. Creating a BSGE recognised Endometriosis Centre in North Wales, with on-going support from the existing endometriosis centres, should be a medium-term priority.

Within endometriosis centres the disciplines outside of gynaecology must be adequately resourced and sustainable, and clerical support provided to ensure a high level of email and telephone follow up.

A clear pathway and a regular Multi-Disciplinary Team meeting, to include representatives from tertiary fertility and endometriosis centres, must be established in order to discuss and prioritise those complex women with fertility and severe endometriosis.

## **CHRONIC PELVIC PAIN**

Pelvic pain management and support must be integrated into the early assessment of women suffering from endometriosis. This can ideally be undertaken by an endometriosis nurse practitioner.

Pelvic floor physiotherapy forms an integral part of CPP management, and physiotherapists with training in CPP should be accessed within secondary care. This will require training of physiotherapists in CPP management.

Tertiary endometriosis services in North and South Wales should have access to a multidisciplinary CPP management service with gynaecologists, anaesthetists, psychologists, physiotherapists, and dietetic input. This should be a rapid access service triaged via the endometriosis nurse practitioner. Options for women from Mid-wales must be facilitated.

## **QUALITY STANDARDS**

The NICE quality indicators when finalised in July 2018 should be adopted in Wales.

All Health Boards should utilise existing diagnostic data, or establish registers of women with endometriosis to facilitate audit.

The number of women added to the BSGE database should be reported to Welsh Government as a quality standard.

## **RESEARCH**

Work with Health and Care Research Wales and the Universities to prioritise and fund projects on the epidemiology and symptom profile of women with endometriosis in Wales.

Priority areas include:

- Development of an effective symptom awareness tool.

- Evaluation of the follow-up processes after surgery and multidisciplinary approach to symptoms management.

- Evaluation of educational resources which are to be developed

- Ongoing monitoring of patient outcomes over time. e.g. via self-reporting to a web resource

**Whilst we acknowledge that these recommendations will take time to implement, immediate consideration must be given to the following issues:**

1) As we write, there are women who have had severe and complex disease diagnosed by their secondary care gynaecologists, told there is nothing that can be done, and discharged without an onward referral to a tertiary, specialist centre for specialist informed decision-making. The Welsh Government could instruct Health Boards that, in such cases, GPs must be allowed to refer directly to the designated specialist centre, to prevent these patients from a) waiting unnecessarily extended periods to be seen in secondary care, and b) entering a costly cycle of repeated, ineffectual appointments and surgeries, as per the recent NICE guidance.

2) There needs to be urgent clarity on the pathway for patients in Mid Wales, including identifying their designated tertiary specialist centre (for example, Birmingham).

3) Cardiff Endometriosis Centre is unable to cope with the current demand for its specialist service. Its waiting lists are escalating, and South Wales patients from outside of Cardiff & Vale are being declined producing inequality in care. An alternative centre outside of Wales could be commissioned centrally to meet the needs of those patients, and that pathway made known to both patients, GPs, and gynaecologists in secondary care.

## **7 Acknowledgments**

Kelechi Nnoaham, Director Public Health Wales, Cwm Taf  
Cardiff University Department of Psychology for assistance with the surveys and data extraction, in particular Hannah Kingwell, Harry Jupp, and China Harrison.  
Welsh Government staff including Holly Williams, Amira Irshad, Richard Chivers, Jonathan Williams and Heather Payne  
The doctors, physiotherapists and women who took part in the surveys and the one-day arts based workshop.

## References

A.J. Cook, C.J. Woolf, P.D. Wall, S.B. McMahon Dynamic receptive field plasticity in rat spinal cord dorsal horn following C-primary afferent input *Nature*, 325 (1987), pp. 151-153

*A Revolution from Within: Transforming Health and Care in Wales*, 2018  
<https://beta.gov.wales/sites/default/files/publications/2018-01/Review-health-social-care-report-final.pdf>.

Ballard et al., 2006 Ballard, K., Lowton, K., Wright, J., What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis, *Fertility & Sterility*, 86, 1296-301, 2006

Byrne D, Curnow T, Smith P on behalf of BSGE Endometriosis Centres, *et al* Laparoscopic excision of deep rectovaginal endometriosis in BSGE endometriosis centres: a multicentre prospective cohort study  
*BMJ Open* 2018;**8**:e018924. doi:10.1136/bmjopen-2017-018924

Denny, E., I never know from one day to another how I will feel: pain and uncertainty in women with endometriosis, *Qualitative Health Research*, 19, 985-95, 2009

European Endometriosis Alliance. (2006). *Endometriosis*. Retrieved from <http://www.endometriosis.org/news/general/historic-decision-for-womens-health-made-by-european-comission/>

Harald Breivik, Elon Eisenberg and Tony O'Brien  
The individual and societal burden of chronic pain in Europe: the case for strategic prioritisation and action to improve knowledge and availability of appropriate care. *BMC Public Health* 2013**13**:1229

Gameiro, S, Bliesemann de Guevara B, El Refaie, E, Payson A. Using a drawing workshop to explore the infertility experiences of Black and Minority Ethnic women in Wales. <http://psych.cf.ac.uk/engagementimpact/thornsandflowers/>

Hsu AL, Sinaii N, Segars J, Nieman LK, Stratton P. Relating pelvic pain location to surgical findings of endometriosis. *Obstet Gynecol*. 2011; 118(2 Pt 1):223–230. [PubMed: 21775836]

Institute of Medicine (US) Committee on Pain D, and Chronic Illness Behavior. The Anatomy and Physiology of Pain. In: Osterweis, M.Kleinman, A., Mechanic, D., editors. *Pain and Disability: Clinical, Behavioral, and Public Policy Perspectives*. Washington, DC: National Academy Press; 1987. p. 123-145.

Latremoliere A, Woolf CJ. Central sensitization: a generator of pain hypersensitivity by central neural plasticity. *J Pain*. 2009; 10(9):895–926. [PubMed: 19712899]

Mihalyi et al. non-invasive diagnosis of endometriosis based on a combined analysis of six bio-markers Human Reproduction vol 25 (3) pp 654 - 664 2010

Nice endometriosis guideline Health Economics Appendix K: Pages 53 – 59)  
<https://www.nice.org.uk/guidance/ng73>

O'Donovan 2017 “Do severe endometriosis patients want specialist pain team management?”

Presented at ESGE 2017 Antalya Turkey

Stratton P, Berkley KJ. Chronic pelvic pain and endometriosis: translational evidence of the relationship and implications. Hum Reprod Update. 2011; 17(3):327–346. [PubMed: 21106492]

Vercelini P, Fedele L, Aimi G, Pietropaolo G, Consonni D, Grosignani PG. Association between endometriosis stage, lesion type, patient characteristics and severity of pelvic pain symptoms.; a multivariate analysis of over 1000 patients. Hum Reprod. 2007; 22(1):266-272

Willard, F. Basic Mechanisms of Pain. In: Audette, JF., Bailey, A., editors. Integrative Pain Medicine: The Science and Practice of Complementary and Alternative Medicine in Pain Management. Totowa, NJ: Humana Press; 2008. p. 19-61.

C.J. Woolf, M.W. Salter Neuronal plasticity: increasing the gain in pain, Science, 288 (2000), pp. 1765-1769

## Appendices

### Appendix 1 FTWW report

The report is accessible via the following link

<http://www.ftww.co.uk/wp-content/uploads/2016/11/Making-the-Case-for-Better-Endometriosis-Treatment-in-Wales-Word-PDF.pdf>



## Appendix 2 Andrew Goodall letter

Cyfarwyddwr Cyffredinol Iechyd a Gwasanaethau Cymdeithasol/  
Prif Weithredwr GIG Cymru  
Grŵp Iechyd a Gwasanaethau Cymdeithasol

Director General Health and Social Services/  
NHS Wales Chief Executive  
Health and Social Services Group



Llywodraeth Cymru  
Welsh Government

Deborah Shaffer  
Fair Treatment for the Women of Wales

Our Ref: AG/AD/TLT

2 February 2016

Dear Ms Shaffer

### ENDOMETRIOSIS CARE IN WALES

Thank you for your letter of 23 November regarding endometriosis care in Wales. My department has been investigating the issues raised in your report and has had discussions with our BSGE-accredited centre in Cardiff and Vale University Health Board.

I welcome the formation of your group and hope we can work together to help improve access and care for those people suffering with this very difficult condition. I am struck by the number of women affected by this disease and the implications this has for the service. I hope you will agree with me that we need a comprehensive service, which meets the needs of women who have varying degrees of disease and pain. In particular, the evidence shows us that the vast majority of women with endometriosis have their disease successfully managed by first and second line medical treatments.

For the small but significant proportion of the women for whom this treatment is not a suitable solution, I agree with you we need to ensure there is equitable access to high quality services based on the evidence of our population's disease burden. I am keen to look into these matters further, the points you raised in your report and the evidence base which underpins the level of service provision we need in Wales.

As you discuss there are workforce and service capacity issues which are challenging but must be grasped. My understanding is the NICE guideline on the management of endometriosis is not due until 2017 but there is a specific interventional procedure guideline on excision or ablation already in existence. Once the full NICE guideline is in place we would expect the service to act on it and consider the implications for their service models. However, at this time the evidence base for excision over ablation is still relatively weak but we should explore whether there is a clinical consensus on its greater efficacy.

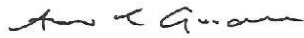


Parc Cathays • Cathays Park  
Caerdydd • Cardiff  
CF10 3NQ

Ffôn • Tel 02920 801182/1144  
[Andrew.Goodall@wales.gsi.gov.uk](mailto:Andrew.Goodall@wales.gsi.gov.uk)  
Gwefan • website: [www.wales.gov.uk](http://www.wales.gov.uk)

I will be commissioning the Women's Health National Specialist Advisory Group to consider the report and provide an analysis. Once we have this piece of work I would be more than happy to arrange a meeting with the relevant policy officials and NHS clinicians to consider the outcomes.

Yours sincerely

A handwritten signature in black ink, appearing to read "Andrew Goodall".

**Dr Andrew Goodall**

## Appendix 3. Terms of reference and membership

### Terms of Reference

- 1.1.1 The current provision of endometriosis in Wales;
- 1.1.2 A proposed robust care pathway for the management of safe, sustainable, high quality and cost-effective endometriosis care including primary, secondary and tertiary care, provided in all settings including remote and rural;
- 1.1.3 Matters relating to workforce planning and the education and training of staff involved in the provision of endometriosis services for NHS Wales.
- 1.2 Quality and outcome measures to monitor the success of the services.

### Membership

- 1.3 Members will be sought to provide multidisciplinary advice on matters relating to endometriosis.
- 1.4 The total membership of the group should reflect equality and diversity of the NHS and service users, as well as a representative of the public and patient voice. Additional members may be co-opted for individual meetings as required to provide balance or appropriate representation.
- 1.5 Professional members are encouraged to utilise the profession they represent and seek their feedback on matters of policy and practice to inform and support the objectives.

### Membership

Jacky Boivin	Department of Psychology, Cardiff University
Lizzy Bruen	Endometriosis Nurse Practitioner Gynaecology, Cardiff and Vale UHB
Emma Cox	CEO Endometriosis UK
Carly Crocker	Swansea Endometriosis Support Group. FTWW member
Andy Glyde	Trustee of Endometriosis UK
Tony Griffiths	Gynaecology, Cardiff and Vale UHB
Abby Hobson	Endometriosis UK. Cardiff Support Group Leader
Deb Jackson	Head of Midwifery and Gynaecology Nursing, ABUHB
Robert Jones	Director N H S Wales Informatics Service
Gurpreet Singh Kalra	Gynaecology, ABMU (Swansea) (replaced by LM)
Geeta Kumar	Gynaecology, BCUHB
Lavinia Marguerite	Gynaecology, ABMU (Bridgend)
Anita Nargund	Gynaecology, ABUHB
Helen Painting	FTWW
Richard Penketh	Gynaecology, Cardiff and Vale UHB (Chair)
Jonathan Pembridge	Gynaecology, Cwym Taf
Debbie Shaffer	CEO FTWW
Lutfi Shamsudin	Gynaecology, Cardiff and Vale UHB
Letchuman Shankar	Gynaecology, Hywel Dda Health Board
Sonia Wartan	Consultant anaesthetist, specialist in pelvic pain ABUHB

## **Appendix 4 Survey of medics Questions**

The Welsh consultants' survey questions can be accessed via the following link  
[https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV\\_2318UqPu3917zHD](https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_2318UqPu3917zHD)

### Responses

The survey report can be accessed via the following link

<https://1drv.ms/w/s!ArCfcHzNpj8mgSd3HEpglRZAta48>

# Appendix 5 and 5a Survey of patients Report

## Working Series 'Endometriosis in Wales: A comparative study on symptom awareness and help-seeking from the patient perspective for women living in Wales and other regions of the UK

J. Boivin, H. Jupp, H. Kingwell  
School of Psychology, Cardiff University

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### Introduction

Endometriosis is a common reproductive disorder affecting about 10% of women. Patients report that the provision of care for endometriosis is suboptimal, leading to very long delays in effective treatment. Delay in treatment could be due to numerous sources: patients could delay seeking help for worrying symptoms, doctors could delay the process of diagnosis, time to diagnosis or treatment could be lengthened due to healthcare system constraints, or to patient delay in uptake of treatment. The United Kingdom has a devolved healthcare system that means women seeking medical attention in any of its constituent countries (Wales, England, Scotland, Northern Ireland) could experience different barriers to effective treatment.

According to the Health Belief Model (Rosenstock, Strecher et al. 1988) diverse factors predict help-seeking behaviour. Faster presentation is associated with perceiving symptoms as threatening (e.g., symptoms perceived to be frequent, severe, worrying), reasons for seeking help outweigh reasons against seeking it, clear direct cues to get help exist (e.g., relative with disease encourages help-seeking) and person characteristics do not modify willingness to seek help (e.g., low disease knowledge, being older or non-white). Patterns of help-seeking are also influenced by the quality and organisation of healthcare. Care pathways that lack clarity, are difficult to comply with, or that do not meet patient need (or leave patients with unmet needs) can often compromise outcomes desired by patients and healthcare providers (e.g., efficient, effective).

The aim of the present mixed method study was to better understand experiences of symptoms and help-seeking in women with endometriosis living in Wales and other parts of the UK. To achieve this aim we undertook two studies. First, was a quantitative survey of women medically diagnosed with endometriosis recruited with the help of two patient advocacy groups (Fair Treatment for the Women of Wales, Endometriosis UK) and through university research panels. Women in Wales were compared to women in other parts of the UK and young women with pelvic or gynaecological symptoms not yet diagnosed. The second study collected qualitative experiential data in a one day arts-based workshop with 14 women living in diverse regions of Wales. This working paper reports the main findings of these studies.

## Methods

### **Participants**

The School of Psychology reviewed and approved the study protocol. The study protocol was developed in collaboration with two patient advocacy groups (i.e., Fair Treatment for the Women of Wales [FTWW], and Endometriosis UK). All participants were 16 years or older. Participants completed a quantitative survey or attended a workshop (or both). The number of women receiving the quantitative survey hyperlink and their eligibility for the study is unknown because women circulated onward through their networks and social media accounts. In total 2237 women clicked the survey link, 925 (41.4%, 925/2237) answered the questions relevant to the present report and of these 744 (80.4%, 744/925) pressed the 'submit' button at the end of answering the survey (a condition required by ethics committee to indicate consent). Women were invited to attend the Arts-based Workshop, and of these 14 were able to attend on the specified date.

### *Quantitative survey*

#### *a. Endometriosis group (N=569)*

Participants with endometriosis (**Endometriosis Group**) were recruited via two patient advocacy websites (i.e., Fair Treatment for the Women of Wales [FTWW], and Endometriosis UK). Incentives for participation were not offered. Participants were assigned to the Endometriosis Group if they reported being diagnosed with endometriosis by a medical doctor. The Endometriosis Group was assigned to Wales (n=136) or Other UK (n=433), according to the reported place of residence.

#### *b. Pelvic or gynaecological (PG) symptom group (N=175, comparison only)*

A comparison group of female university students experiencing 'pelvic or gynaecological symptoms' were recruited from a Welsh university. Participants were invited through the School of Psychology Experiment Management System (EMS) and students that participated in exchange for credits. None of the women had been medically diagnosed with endometriosis. Participants were currently living in Wales due to their studies.

#### *Qualitative workshop: Welsh women medically diagnosed with endometriosis (N=14)*

Women from the advocacy group FTWW were invited to attend a one-day drawing workshop to provide more in-depth information about their symptoms and help-seeking.

### **Materials**

This mixed methods study utilised two methodological approaches to collect data on the experience of symptoms and help-seeking, and these are described in the following sections.

The 'Symptom and Help-seeking Survey' was created for the present study. The survey was similar for the Endometriosis and Pelvic & Gynaecological group but wording and questions were adapted to be relevant for each group. After agreeing to participate in the study participants confirmed whether or not a medical doctor had diagnosed their symptoms with endometriosis. Those who declared 'yes' were assigned to the Endometriosis group and completed the 'Symptom and Help-seeking Survey' in relation to endometriosis symptoms and help-seeking. Those who declared 'no' completed this questionnaire in relation to 'pelvic or gynaecological symptoms'. See Appendix 5.a. for more detailed information about methodology.

'Symptom and Help-seeking Survey' was based on the Health Belief Model, which is a theoretical model to explain help-seeking behaviour. The questions were related to symptom burden (number, frequency, perceived severity, and worry about symptoms), (b) cues to support action (e.g., relatives with endometriosis, endometriosis knowledge), (c) importance of pros and cons of seeking medical advice, and (d) modifying individual factors that could increase or decrease likelihood of taking action (e.g., age, ethnicity, country of residence) and (e) help-seeking behaviour in particular the age at which they had started worrying about symptoms, sought medical advice, received a diagnosis, and were treated (see "Study variables", Appendix 5a). The help-seeking section also comprised questions about experiences when first consulting the GP for symptoms (e.g., number of visits, referrals). Overall perceptions of care so far were also solicited. At the end of the survey participants were asked socio-demographic questions (e.g., age, education).

The arts-based workshop ('Drawing Out Health', Gameiro et al. website) is based on the premise and existing literature showing that drawing is a particularly effective method to elicit thoughts and feelings about sensitive topics (such as health) especially when personal experiences may otherwise impact the ability to express experiences of health (e.g., medical complexity, minority status, health literacy). Briefly, the one-day Drawing Out Health workshop (described in detail in Appendix 5.a) involves a set structure where women are taught basic drawing techniques, asked to draw around specific themes relevant to the health topic, present and discuss their drawings with the group (if willing), after which key messages from the group are compiled into a booklet for dissemination by women, and public engagement (anonymous). Advantages of this methodology include it being more inclusive than verbal-only methods, being unstructured, open-ended and non-directive allowing for highly personal perspectives to emerge, sharing experiences that enable central themes to be developed, and outputs (booklet) that facilitate broader sharing and engagement about the health topic outwith the group (Gameiro et al.). Three drawing activities were used to collect data. First, women were asked to **draw a self-portrait** and share it with the group. Second, participants were asked to **draw their symptom experiences**: 'If endometriosis was an object, creature or animal or weather, what would it be?'. Third, participants were asked to **draw their experiences of healthcare**: 'How would you draw your relationship with medical staff?' After each exercise participants shared their artwork with the group, followed by group discussion of emerging views. Three researchers facilitated the workshop (rationale for research, DrawingOut Health methodology, drawing techniques) and the workshop audio recorded. Recordings were transcribed and analysed see Appendix 5.a for full details).

## **Data analysis**

Descriptive statistics (percentages, means) and independent inferential tests (t-tests, analysis of variance) were used to compare groups on quantitative survey data. Thematic analysis was used for qualitative data elicited from the workshop according to well-established analytic approaches. Details in Appendix 5.a.

## **Results: Quantitative survey**

### *1) Participant characteristics*



**Table 1** shows characteristics of the study groups. The Endometriosis groups (Wales, Other UK) were similar in age and educational background. The Wales Endometriosis group was more likely to be British, in a relationship and to have given birth (versus Other UK, PG groups). Although the Endometriosis groups were equally likely to be in full time work, more women in Wales were unemployed (20.0% versus 11.1%), and more reported poor or very poor health (42.6% versus 29.8%).

**Table 1** Descriptive statistics for demographic characteristics in the Endometriosis Group according to country of residence<sup>1</sup>

Variable	Wales (n=136)	Other UK (n=433)	Pelvic & Gynaecol (n=175)	Statistic
<b>Age, years M (SD)</b>	34.87 <sup>a</sup> (7.63)	34.35 <sup>a</sup> (8.33)	26.27 <sup>b</sup> (8.6)	64.74 <sup>**</sup> *
Age groups n (%)				
19 - 25	16 (12.3)	62 (14.7)	101 (58.4)	
26 - 40	87 (66.9)	264 (62.4)	58 (33.5)	
41 to 70	28 (20.8)	96 (22.7)	14 (8.1)	
<b>Ethnic origin n (% White British)</b>	129 (94.9) <sup>a</sup>	382 (88.2) <sup>b</sup>	145 (82.9) <sup>b</sup>	10.6 <sup>**</sup>
<b>University Education n (% yes)</b>	73 (53.7) <sup>a</sup>	264 (61.0) <sup>a</sup>	----	2.3
<b>Employment n (%)</b>				9.39 <sup>*</sup>
Full time	73 (53.7) <sup>a</sup>	254 (58.7) <sup>a</sup>	----	1.05
Unemployed	27 (20.0) <sup>a</sup>	48 (11.1) <sup>b</sup>	----	6.95 <sup>**</sup>
<b>Relationship status n (%)</b>				
In a relationship (married, cohabitating, together apart)	124 (91.2) <sup>a</sup>	349 (80.6) <sup>b</sup>	121(69.1) <sup>c</sup>	23.5 <sup>***</sup>
<b>Ever given birth n (% yes)</b>	65 (47.8) <sup>a</sup>	164 (37.9) <sup>b</sup>	37 (21.1) <sup>c</sup>	4.2 <sup>*</sup>
<b>Self-reported health n (% poor or very poor health)</b>	58 (42.6) <sup>a</sup>	129 (29.8) <sup>b</sup>	40 (22.9) <sup>c</sup>	14.4 <sup>***</sup>

Note. <sup>1</sup>Ns vary slightly due to isolated missing data. Values (means, percentages) with different superscript letters are significantly different from each other. \* p < .05

\*\* p < .01

\*\*\* p < .001

## **2) Symptom profile of endometriosis versus other pelvic and gynaecological symptoms groups**

**Table 2** shows descriptive statistics for symptom profiles. The Endometriosis groups recalled their symptoms starting at a similar age (early 20s) and a similar percentage (about 15%) had a mother or sister with endometriosis. In terms of symptom profile, women in Wales reported a greater number of

symptoms, a greater percentage experienced daily, and more severe symptoms than the Other UK group and the PG group. The two Endometriosis groups (Wales, Other UK) had a greater symptom burden in all respects (number, frequency, severity) than did the Pelvic & Gynaecological group, except for worry about the symptom that was less in the Endometriosis group. **Table 3** shows the percentage of women reporting any experience of each symptom in the symptom profile list (generated through research and advocacy groups). The comparison tests show that a major distinguishing feature was that more women in the Endometriosis group reported daily experience of symptoms than did women in the comparison group of undiagnosed pelvic and gynaecological symptoms.

**Table 2** Descriptive statistics for symptom profile for the Endometriosis Group according to country of residence

Variable	Wales (n=136)	Other UK (n=433)	Pelvic & Gynaecological (PG) (n=175)	Statistic
<b><i>Age of onset and family background</i></b>				
Average age at symptom start	21.60 (5.66) <sup>a</sup>	22.87 (6.37) <sup>a</sup>	20.0 (6.1) <sup>b</sup>	12.60*
Mother, sister with endometriosis n (%)	21 (15.4) <sup>a</sup>	52 (12.0) <sup>a</sup>	40 (22.9) <sup>b</sup>	11.40**
Any other female relative with endometriosis n (%)	78 (57.4) <sup>a</sup>	214 (49.4) <sup>b</sup>	75 (42.9) <sup>b</sup>	6.4*
<b><i>Symptom profile</i></b>				
Nbr of symptoms M (SD)	10.18 (3.1) <sup>a</sup>	9.22 (3.1) <sup>b</sup>	7.41 (3.3) <sup>c</sup>	33.43**
Total Symptom burden M (SD)	173.55 (77.0) <sup>a</sup>	151.64 (75.66) <sup>b</sup>	122.9 (69.5) <sup>c</sup>	17.5***
% symptoms daily M (SD)	.51 (.25) <sup>a</sup>	.43 (.27) <sup>b</sup>	.29 (.26) <sup>c</sup>	29.89***
Mean symptom severity M (SD)	3.89 (.56) <sup>a</sup>	3.71 (.59) <sup>b</sup>	3.34 (.70) <sup>c</sup>	37.08***
Mean symptom worry M (SD)	2.20 (.67) <sup>a</sup>	2.33 (.76) <sup>a</sup>	2.88 (.94) <sup>b</sup>	37.09***
<b><i>Self-reported time intervals and doctor visits</i></b>				
Total time interval between worrying symptom awareness and treatment (in years) M (SD)	9.43 (7.1)	8.50 (6.87)	-	1.30
Symptom awareness to seeking advice	1.66 (3.21)	1.63 (3.92)	-	.07
Seeking advice to diagnosis	7.56 (7.18)	6.53 (6.48)	-	1.56
Diagnosis to treatment	.52 (1.76)	.32 (1.33)	-	1.38
Estimated number of doctor visits before diagnosis M (SD)	26.0 (34.1)	19.89 (32.0)	-	1.79
Nbr more than 20 visits n (%)	51 (37.5)	115 (26.6)	-	5.86*
<b><i>Reported thoughts and feelings about diagnostic process</i></b>				
Emotional reaction to diagnosis				
Negative emotions	.391 (.22)	.373 (.22)	---	.76
Positive emotions	.142 (.14)	.166 (.16)	---	1.60
<b><i>Overall view of healthcare</i></b>				
Satisfaction with medical experiences	2.41 (.87)	2.46 (.87)	-	.56
How often feel like giving up	3.36 (1.4)	3.01 (1.38)	-	2.56*

Notes. \*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

**Table 3**

Percentage of women reporting experience of symptom according to country of residence and versus women experiencing pelvic and gynaecological symptoms not diagnosed as endometriosis

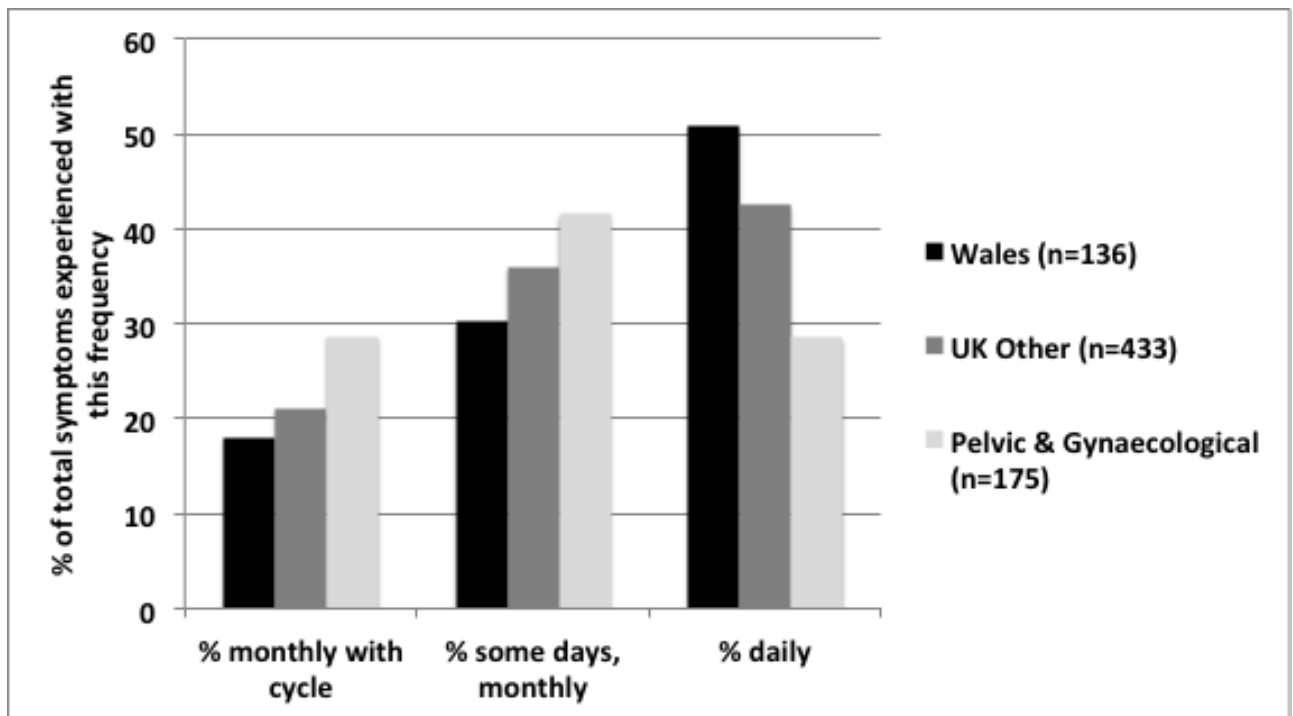
	Endometriosis		Pelvic & Gynaecological <sup>1</sup>	Chi value	Comparison tests <sup>2</sup> E = Endometriosis PG = Pelvic & Gynaecological
	Wales (n=136)	Other UK (n=433)	Wales university students (N=175)		
<b>Symptom</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>		
Period pain/affects daily activities & QoL	132 (97.1)	416 (96.1)	161 (92.0)	29.2***	E > daily: 41.2% vs 19.9%
Cyclical pelvic pain	134 (62.9)	308 (71.1)	29 (16.6)	10.5*	E > daily: 49% vs 34.9
Chronic pelvic pain (pain felt below your belly button) for at least 6 months	133 (97.80)	402 (92.8)	108 (61.7)	21.7***	E > daily: 72.2% vs 50.9%
Pain and discomfort when passing water	87 (64.0)	258 (59.6)	79 (45.1)	10.8*	E > daily: 38.9% vs 21.5%
Pain and discomfort during bowel movement	125 (91.9)	357 (82.4)	105 (60.0)	18.5***	E > daily: 60.6% vs 39.0%
Pain during or after sex	120 (88.2)	345 (79.7)	115 (65.7)	16.6**	E > daily: 60.6% vs 43.5%
Unexplained cyclical pain under ribcage	83 (61.0)	232 (53.6)	62 (35.4)	11.9*	Daily frequency reported: 39.2% Other UK; 51.8% Wales; 27.4% PG
Shoulder tip pain	69 (50.7)	167 (38.6)	49 (28.0)	4.4	
Difficulty emptying bladder	76 (55.9)	242 (55.9)	71 (40.6)	17.8***	E > daily: 48.5% vs 22.5%
Heavy periods (bleeding could soak through your clothes/using pads & tampons together)	119 (87.5)	345 (79.7)	137 (78.3)	5.6	
Blood in urine	46 (33.8)	133 (30.7)	31 (17.7)	10.1	Wales > daily: 28.3% vs 13.2%
Rectal bleeding	69 (50.7)	176 (40.6)	58 (33.1)	9.1	
Coughing up blood	9 (6.6)	22 (5.1)	2 (1.1)	1.1	
Breathlessness,	68 (50.0)	184 (42.5)	72 (41.1)	8.2	
Feeling tired all the time	129 (94.9)	397 (91.7)	150 (85.7)	12.31*	Wales > daily: 89.9% vs 77.0%

Note. <sup>1</sup>Pelvic or gynaecological (PG) = University students with pelvic or gynaecological symptoms not diagnosed as endometriosis. <sup>2</sup>Frequency of experience 'monthly with period', 'some days, monthly', 'daily, most days'; 'E= Endometriosis group incl Wales and Other UK, QoL = Quality of Life

**Figure 1** shows the difference in frequency of daily symptoms among groups. The Endometriosis groups (especially living in Wales) were more likely to experience daily symptoms, whereas the Pelvic and Gynaecological groups were more likely to have cyclical or less frequent symptoms.

**Figure 1**

Percentage of total symptoms experienced at each frequency 'monthly with period', 'some days, monthly', 'daily, most days' according to group

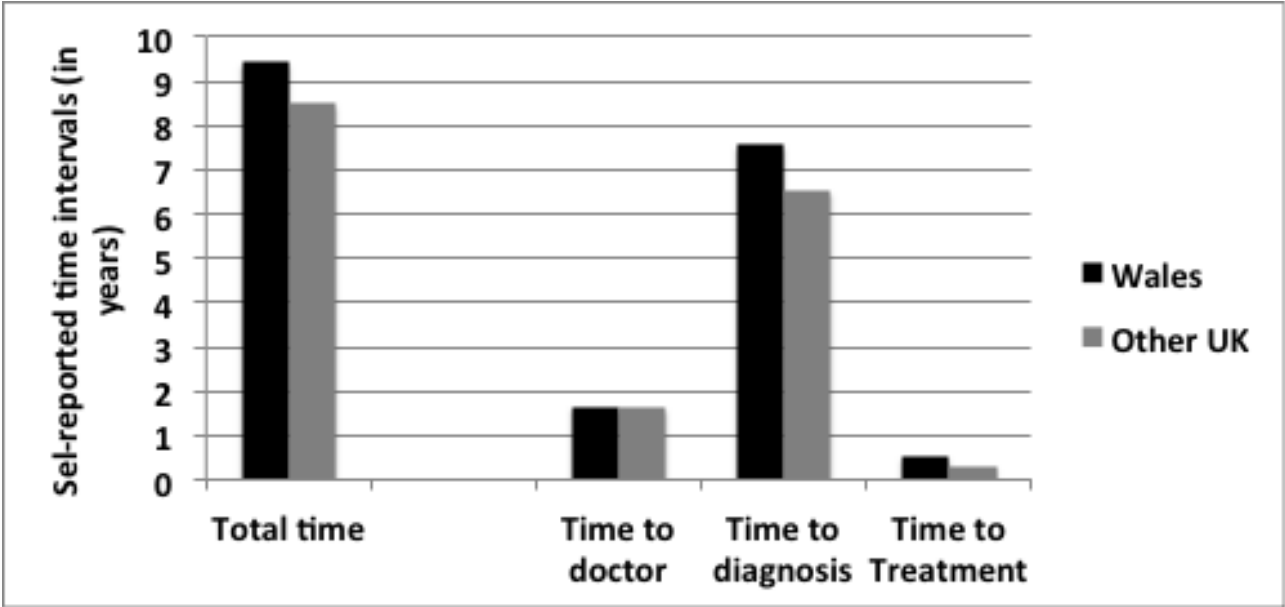


### 3) Help-seeking and perceptions of provision of care

The Endometriosis groups were similar in helping seeking patterns with time intervals. **Table 2** shows that the total time interval between symptom awareness and treatment was 9.43 years for women in Wales and 8.50 years for women in the Other UK group. When this time delay was decomposed into its constituent elements, the longest reported time interval is between women presenting to the doctor and getting a diagnosis (see **Figure 2**, about 7.5 years in Wales versus 6.5 years in Other UK). Women in Wales reported more medical visits to achieve a diagnosis (26 versus 20 visits), with significantly more requiring 20 or more visits (20% reported more than 40 visits versus 12.2% in Other UK) (see **Table 2**). Note that 8.8% of women in Wales and 5.5% in Other UK reported having had too many visits to provide an estimate. Logistic regression analysis indicated that predictors of a longer diagnostic time interval were having an older age at start of symptoms, reporting negative experiences at first consultation (e.g., disbelief doctor, misdiagnosis). There was a trend for having a close relative with endometriosis (mother, sister) to be associated with a shorter time to diagnosis.



**Figure 2:** Total time interval between symptom awareness and first treatment, and decomposed into its constituent time intervals



Participants in the Endometriosis group reacted negatively to the diagnosis of endometriosis (see **Table 2**) but 29.2% felt validated by the diagnosis. The Endometriosis groups were similarly satisfied with their experiences of care thus far (seldom satisfied), but significantly more women in Wales than Other UK felt like giving up on having their symptoms explained or diagnosed. As shown in **Table 4**, the majority of participants in the Endometriosis groups believed that the doctor contributed to the delay in getting a diagnosis (about 80%). The Endometriosis groups were very similar in the reasons for believing this with the most frequently endorsed reasons being the doctor not believing the symptom profile (about 60%), being given medication that was not sufficient (60%) and misdiagnosis (through judgement or false negative testing).

**Table 4** Number (percentage) of patients that believe doctor caused a delay getting a diagnosis and reasons for that belief according to Endometriosis group

Perceived reasons for doctor causing delay	Wales (n=136) n (%)	Other UK (n=433) n (%)	Chi square
Believe doctor caused a delay in getting a correct diagnosis n (%) yes	104 (78.2)	340 (80.4)	.30
<i>Reasons endorsed:</i>			
Doctor didn't believe the severity of my symptoms or thought it was normal pain	89 (65.4)	275 (63.5)	.68
The doctor thought my symptoms were due to mental health problems (for example, stress, anxiety or depression)	33 (24.3)	105 (24.2)	.00
The doctor said I was too young or too old to have endometriosis	28 (20.6)	51 (11.8)	6.71**
The doctor initially diagnosed me with something other than endometriosis	47 (34.6)	122 (28.2)	2.0
I had an ultrasound that failed to detect my endometriosis	46 (33.8)	143 (33.0)	.86
Abnormalities were detected but were not considered important or acted upon at the time of discovery	13 (9.6)	45 (10.4)	.08
I was first prescribed the oral contraceptive pill to relieve symptoms, but later needed alternative hormonal therapies	94 (69.1)	316 (73.0)	.38
I had to unnecessarily repeat tests that delayed the process (e.g., ultrasounds, pregnancy tests, sexually transmitted diseases)	34 (25.0)	92 (21.2)	.85
The doctor told me to get pregnant to reduce symptoms of endometriosis	25 (18.4)	70 (16.2)	.36
The doctor said they could not refer me because the system would not allow it)	13 (9.6)	23 (5.3)	3.1 <sup>t</sup>

### Results: Qualitative workshop

Women in the Workshop were on average 34 years of age (4 < 30 years), 8 had an undergraduate or postgraduate degree and average years since diagnosis was about 8 years.

The one-day workshop generated 4447 verbatim sentences that could be coded. The content of these sentences generated 119 codes. The researchers (HK and JB) grouped these 199 codes into 20 thematically related categories. In the final step of the analyses these thematic codes were abstracted into the four broad themes of the workshop. **Table 5** shows how codes were clustered into five broad themes, of which four were considered central to the workshop findings. **Figure 3** illustrates the four broad themes and their links.

Table 5 Thematic categories subsumed under each broad themes (in bold) for women's experiences of endometriosis (N=4447 coded elements)

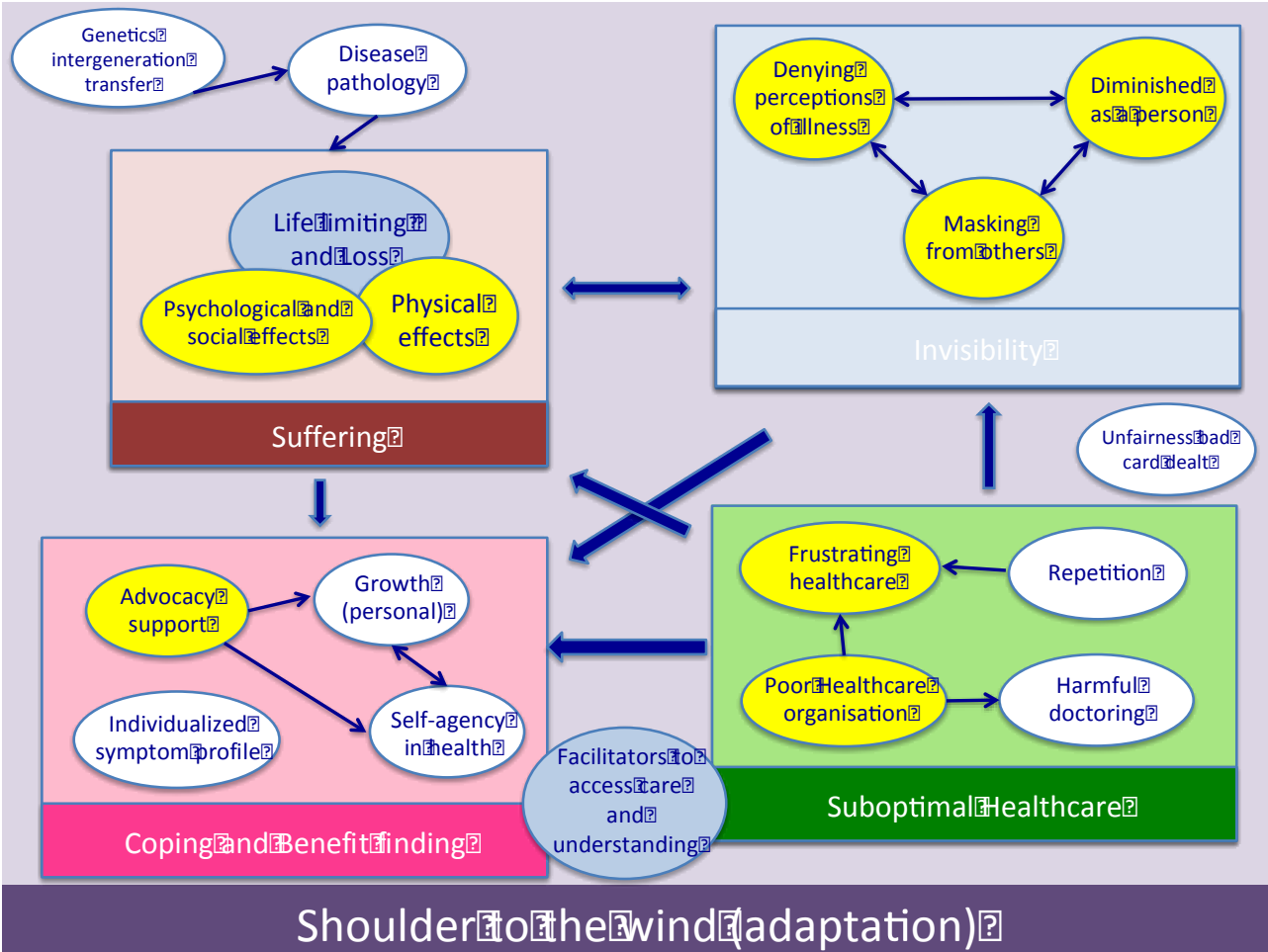
<b>Broad themes</b>	%	n
Underpinning thematic categories		
<b>Disease reference</b>	<b>12.82</b>	<b>438</b>
Disease pathology	11.89	417
Genetics intergeneration transfer	0.93	21
<b>Suffering</b>	<b>41.92</b>	<b>1348</b>
Psychological and social effects	19.29	675
Physical effects	11.41	324
Life limiting	5.21	172
Loss	6.01	177
<b>Invisibility</b>	<b>23.38</b>	<b>776</b>
Denying perceptions of illness	16.87	607
Diminished as a person	4.92	124
Masking from others	1.59	45
<b>Sup-optimal healthcare</b>	<b>35.36</b>	<b>1203</b>
Frustrating healthcare	13.45	418
Poor healthcare organisation	18.35	693
Harmful doctoring	3.56	92
<b>Coping and benefit finding</b>	<b>25.17</b>	<b>814</b>
Advocacy support	11.47	408
Growth (personal)	5.53	156
Self-agency in health	3.29	107
Individualized symptom profile	4.88	143
<b>Other</b>	<b>23.46</b>	<b>695</b>
Facilitators to access care and understanding	2.31	47
Unfairness (resentment) bad card dealt	3.91	97
Poor health due to other factors	1.41	46
Issues emerging from research	3.01	67

n= number of times thematic category was mentioned by any participant

%= percentage of coded data (verbatim sentences) linked to thematic category

NB: The sum '%' and 'n' for the broad themes do not add up to 100% (i.e., n=4447) as some codes feature in more than one thematic category

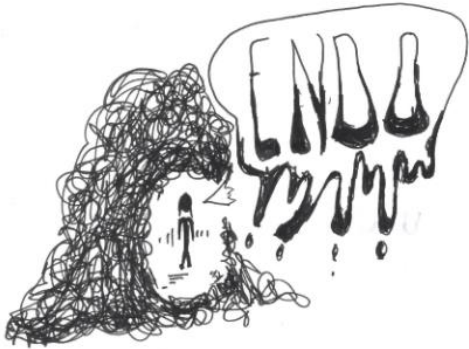

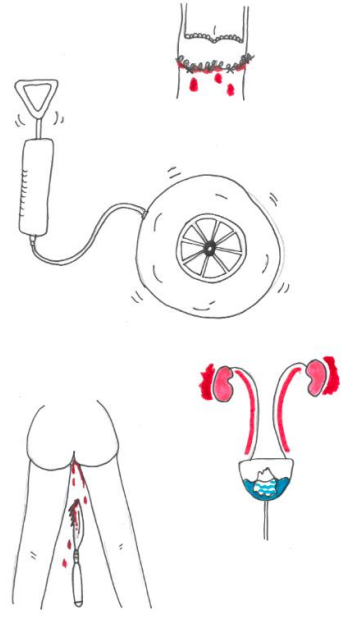
**Figure 3 Thematic representation of the four broad themes to emerge from the arts-based DrawingOut Health workshop**



The broad themes are briefly described in the next sections, with a full report forthcoming.

## I. Endometriosis is suffering

As shown in Figure 3 and Table 5 much of the coded data referred in some way or another to the suffering women experienced as a result of their condition. The suffering was physical and psychological, considered to be life limiting and associated with significant loss. These quotes and drawings illustrate this suffering.

<p>IL: me the thing that like I just remember or just features really really heavily is heaviness (.) so I always feel dragged towards the ground in some way (.) so it was like- when I was looking at the bubbles and stuff I don't know it felt right that everything just sort of gets pulled down or just almost like melts down so everything has kind of- I tried to put that in the lettering where it's heavy at the bottom and everything just feels like oh just tugged downwards so that's what (.) that's the overarching like</p> <p>ED: that's almost like- that picture there is almost like you're being devoured by a monster</p> <p>LI: yeah and it's kind of (is)</p>	
<p>AD: my drawings are- there's two of them but they're both of me like curled in the foetal position crying (.) er and my thoughts are basically I can't take this anymore and I don't want to carry on like this (.) cos that's how it makes you feel (.)</p> <p>EJ: you're not alone in that</p> <p>RJ: I was gonna say how many- how many of us in here have considered suicide [show of hands] look at all the hands (.)</p>	
<p>um ...that's the barbed wire on the bra (.) cos I get a lot of pain upper abdominal pain and like under the ribs (.) that's a pump going to a tyre that's overinflated and it's gonna burst cos when you get bloating you literally feel like you're gonna pop (.) I don't know if you can tell what that is but it's an iceberg in my bladder cos I get this weird cold sensation symptom (.) ... yeah um that's a knife (.) sorry that's a bit graphic that's a knife going into the rectum...</p>	



## II. Invisibility through the eyes of others and self

Three themes were linked to this broad theme. Women often expressed that because endometriosis was not visible others often would not believe in the severity of the illness. These denying social perceptions made it more difficult for people to talk about their disorders. Women often felt they had to present a brave face, deny the extent of their suffering or in other ways hide to meet with what they perceived were the (at times judgemental) perceptions of doctors, and other people in their social environment. Invisibility was also shown in the diminishing effect of patronising healthcare or of feeling diminished as women (less feminine, less able, less confident). This invisibility is illustrated in the following drawings and quotes.

<p>...you look perfectly normal nobody can see your scars; they're hidden away. Nobody can see your pain and you wear a mask all of the time you tell people that you're fine and everybody thinks that you're- (.) but really [sigh] that's how I really see myself that's how I look without my make-up that's how I feel about myself.</p>	
<p>EJ: ... a vase yeah ... what once was light bright and beautiful now hides in dark, cracked, damaged and broken because that is how I feel quite frankly. ... I put on my face and I put on my yellow bits and let you all see me smiling but if you saw me at home I don't look like this (.) I don't stand up straight I walk around my house like a granny with a hot water bottle shoved down the front of my pants down the back of my pants (.) I'm constantly trying to do anything I can to make myself feel better so that I can get back out and help other people feel better because (.)</p>	
<p>MS: ... um so I drew- that's the doctor (.) the big one there (.) the big stick and then that's me tiny little insignificant me and um a six foot high wall with razor wire and everything across the top of it</p>	





specific part of you and go well that's fine so you go back on the tread

#### IV. Coping through benefit finding and shared experiences

Women managed to cope with their illness by taking their health and healthcare into their own hands. All expressed that an important way in which they were able to achieve this and cope was through the advocacy group. All the women in this workshop had been recruited through Fair Treatment for the Women of Wales but women expressed gratitude for other groups through the experiences they had had over the long years of coping with the illness.

AL: it's the best thing I've ever done and I really mean that joining FTWW.

RJ: I remember telling my husband I'm like oh my god this is the most amazing group ever

EJ: for me the only way I can become (not) so broken anymore is by trying to help fix the whole scenario that we're living in cos it's just not good enough

YL: I wouldn't have started the Swansea group (support group) if I hadn't had the confidence that I got through finding FTWW I know that for certain



ED: maybe at last our voices are going to be heard (.) I- um so the fact... that Welsh government listen to patients you know how amazing is that ... my god you know if this really does happen (change in provision for endometriosis in Wales) ... just imagine how wonderful it would be if Wales led the way on endometriosis



AL... just the fact that this today is happening just the fact that new medics like Hannah (medical student facilitating the workshop) are going into the profession and are interested in and want to know is- is encouraging.

## V. Over-arching theme: Shoulder to the wind (adaptation)

The overarching theme of the workshop referred to the adaptation the women made to carry on with life despite the significant suffering, invisibility afforded to their condition (and diminishing selves) and the inefficient, fragmented and at times chaotic healthcare to which they were exposed. This adaptation was achieved largely through self-agency and connecting together as women (through advocacy groups) and developing strong bonds of connection.

...when it's actually blowing a gale you're facing forward and trying to push forward through all of that with sort of like a bit of weight from there pulling you backwards and it's just like you've got to keep going cos where you need to be is over there but every force possible is pushing you back (.)



## Conclusions

The results are compelling in showing that women with endometriosis living in Wales suffer greatly from their condition and this suffering is linked to the suboptimal healthcare they believe they receive. A limitation of the study is that participants with endometriosis were recruited through advocacy groups. It could be that women seeking out such groups have worse disease profiles or in other ways differ from those not linked to advocacy groups. We acknowledge this limitation and support further controlled research. However, we also note that > 500 women participated in the studies and that we used a comparison group of women with undiagnosed pelvic and gynaecological symptoms (175 women) which helped mitigate bias from sampling. Participants in Wales were found to have a more severe disease burden (i.e., more symptoms, more frequently experienced and of greater severity), to require more consultations to achieve a diagnosis (26 visits) and to have a longer time to diagnosis (7 to 8 years) than women in other parts of the UK. It could be that greater disease burden means that women in Wales have more complex disease that is more difficult to diagnose. However, we would argue the reverse; greater disease burden is a consequence of the inefficient care pathway and long delay in diagnosis that allows the disease to progress to a worse state. The majority of participants in Wales and other parts of the UK reported unsatisfactory early medical consultations that minimised or normalised their symptoms, that subjected them to unnecessary repeat testing, and that often led to incorrect diagnoses or ineffective first treatments requiring further, more invasive treatments at a later date. Together these findings suggest that the current care pathway is not efficient, and attracts additional costs to the national health service in Wales through physical disease progression and through additional health services to manage suffering (e.g., depression, pain management) and potentially through other lost opportunities. Indeed participants living in Wales were two times more likely to be unemployed despite being as educated as their counterparts in other areas of the UK. Our results strongly support further investigation of the care pathways for endometriosis in Wales, more research into development of educational resources for doctors about endometriosis and young girls about menstrual health and development of support tools for women with endometriosis. The findings of the workshop made clear that women felt fortunate in finding support and information through

advocacy groups that helped them strengthen their resilience and coping. Despite strong evidence of coping in the face of adversity care for women with endometriosis in Wales should be re-evaluated.

## **Appendix 5.a Detailed description of quantitative survey questions and qualitative drawing workshop**

### **I. Quantitative survey**

'Symptom and Help-seeking Survey' was based on the Health Belief Model, which is a theoretical model to explain help-seeking behaviour. It comprises factors predicting the help-seeking from the person perspective. These include: (a) symptom burden (susceptibility, severity to disease), (b) cues to support action, (c) pros and cons of taking action, and (d) modifying individual factors that could increase or decrease likelihood of taking action (e) help-seeking factors and (f) experiences of care.

#### ***a) Symptom burden***

Symptom burden was the cross product of the frequency of symptoms, their perceived severity and extent of worry about the symptoms. The 15 symptoms were: period pain that affects daily activities and quality of life, heavy periods (bleeding so heavy it could soak through your clothes or using pads and tampons together), chronic pelvic pain (pain felt below your belly button) for at least 6 months, pain during or after sex, pain and discomfort when passing water, difficulty emptying bladder, blood in urine, pain and discomfort during bowel movement, rectal bleeding, unexplained cyclical pain under ribcage, cyclical pelvic pain. Four non-specific symptoms were also included on advice of advocacy groups: shoulder tip pain, breathlessness, coughing up blood, feeling tired all the time. Participants were asked to indicate frequency of each symptom, then grouped in three categories ('daily, most days', 'some days, monthly', 'monthly with my period' coded, 3, 2, 1, respectively). Physical severity ("How severely you experience each symptom?") and worry ("How worried are you about each symptom?") were each rated on 5-point response scales from 'not at all' to 'extremely' (1 to 5). Product scores (frequency X severity X worry) for each symptom were calculated and summed to produce a Total Symptom Burden score (range: 15 to 1125) for each person.

#### ***b) Cues to support action***

The cues to action were factors that would increase perceptions that symptoms were worthy of seeking medical help. The factors were: having a mother or sister with endometriosis (no, yes), any other relative with endometriosis (no, yes), age at which symptoms started and actively trying to become pregnant (yes, no).

#### ***c) Pros and cons of seeking help***

The reasons for or against seeking help were generated based on extant literature on reasons for help-seeking, discussion with advocacy groups and the recent NICE Guideline. There were 19 reasons for seeking help (e.g., desire to stop symptom, pain too severe) and 15 reasons against (e.g., too embarrassed, thought symptoms were normal). Participants rated to what extent these reasons had been important in motivating their decision about seeking medical help on a five-point response scale (strongly disagree to agree). Responses were averaged across items within each set (pros, cons) with higher scores indicating more of the attribute (more pro, more con). In addition, cons were subtracted from the pro score to create a facilitated help-seeking score (higher scores indicated pros outweighed cons).

#### ***d) Modifying factors***

Four modifying demographic factors known to affect help-seeking were also collected and were: age, ethnic origin (British, non-British), country of residence (Wales, versus other-UK) and relationship status (in a relationship, not in a relationship) as well as knowledge about endometriosis. The Endometriosis Knowledge Scale (EKS) was created for this study and comprised eleven statements culled from existing research, key messages issued from advocacy groups, and content from the NICE guidelines (2017). The items included facts about endometriosis prevalence, symptoms and treatments. The Cronbach reliability coefficient was satisfactory (.74 for the set of 11 symptoms). Questions were scored and a total correct score was converted to a percentage (0 to 100% correct). The Endometriosis group was additionally asked about what they thought could help detect endometriosis (laparoscopy, blood tests, scans, x-rays, pelvic exams, colonoscopy, MRI).

#### *e) Help-seeking behaviour*

Diverse aspects of seeking help were investigated. Delay was computed based on answers to four age questions, as per Bougale et al. (2017): age started thinking one or more of your symptoms were not normal; age went to see a doctor about your symptoms; age were given a diagnosis of endometriosis, and; age were first treated for endometriosis. From these variables we computed four time intervals: (1) **help-seeking interval** which was time between worrying symptom awareness and first consulting doctor, (2) **diagnostic interval** which was time between first consulting doctor and receipt of a diagnosis; (3) **treatment interval** which was time between diagnosis to receipt of first treatment [whether effective or not], and; (4) **total time interval** which was time between worrying symptom awareness and first treatment. Participants had the option to indicate that they had never been treated but all were diagnosed as a condition of the study. Time variables were expressed in [fraction] of years, with 0 indicating no time interval and > 0 indicating at least some [fraction] of years.

Although women in the **Pelvic Gynaecological Group** were asked these questions, too few had consulted a medical doctor about their symptoms (n=36, 20.6%) to analyse separately, and therefore they were excluded from analyses using the time interval variables.

#### *f) Experiences of care for endometriosis (Endometriosis group only)*

Women were asked to inform on their experiences of care at the time of first consultation. First, were questions about the **number of medical consultations prior to diagnosis** (“estimate the number of visits you made to your doctor prior to your diagnosis of endometriosis”) and how easy or difficult it was to see a doctor (very difficult to very easy). Second, were questions about **what the doctor did at this first consultation** (“did the doctor explain what could be the cause of symptoms”, “did the doctor refer you for tests”, yes, no) and what were **tests in referral** (blood urine, sexually transmitted infections, x-rays, scans, including the option of not being referred for further testing). Third, were questions about the **emotional and cognitive reactions to diagnostic consultations**. Emotional reaction to diagnosis comprised 8 negative and 8 positive emotions, 4 uncertainty reactions, and 1 appraisal (validation) question suggested by advocacy group. Cognitions included **perceptions the doctor had caused a delay in diagnosis** (yes, no), and if yes **reasons for this belief** (e.g., normalised symptoms, first provided oral contraceptives but needed other hormonal preparations, had scan that failed to detect endometriosis, initial diagnosis was other than endometriosis, unnecessary repetition of test [e.g., scans, pregnancy tests, STI tests], recommended to get pregnant to reduce symptoms, symptoms were ascribed to mental health problems, not referred for tests due to constraints of

system). Finally participants were asked to provide an over view of **satisfaction with medical care so far** by indicating how frequently they were satisfied with medical experiences thus far (“Taking all of these experiences together how often were you satisfied with your medical consultations”) from (never, seldom, quite often, very often, always). Similarly, people indicated to what extent experiences this far caused people felt the **desire to give up on healthcare** (“Taking all these experiences into account did you ever feel like giving up trying to get your symptoms explained (or diagnosed)?”) from (never, to always).

### *Data analysis*

Data were examined to determine suitability for analyses (data screening, missing data analyses). Data screening included recoding data into numeric values where these entered as textual data (e.g. ‘8 weeks’, was converted to ‘8’). ‘Number of doctor visits’ was difficult for people to estimate because of the high number of appointments many women had experienced. For number of doctor visits the decisions were: if people indicated an amount over a specific number (e.g., 10+ visits) the value entered was the minimum (i.e., 10); if a range was provided (i.e., 30 to 40 visits) the mid-range was entered (35). People who indicated inadvertent discovery of endometriosis (e.g., upon examination for appendicitis, cervical cancer) were given a code of zero to recode this possibility. However, because the latter biases the number of visits downward, these participants were indicated separately. If people indicated the number of years of appointments instead of number of visits they were coded as ‘missing’. If people indicated ‘too many to count’ they were coded separately. One outlier (480 visits) was excluded from analysis. Note that the question asked ‘number of visits made to your doctor prior to diagnosis’

## *II. Qualitative Workshop*

The Endometriosis workshop followed the recommended format (see Gameiro et al for full details). The workshop started with an ice-breaking activity to allow participants and researchers to introduce themselves. Issues about the group format, respect and confidentiality were discussed and agreed. Participants were introduced to the basics of drawing (how to draw things and people) and guided through some simple drawing exercises (e.g., transforming plain circles into an object of their choice, a face expressing an emotion, etc). Participants were encouraged to use colour as they thought appropriate. The participants were then introduced to the concept of visual metaphor, defined simply “...as the use of something visible to show something that is invisible” (Gameiro et al) with examples provided. Three drawing activities were used to collect data. First, women were asked to **draw a self-portrait** and share it with the group. Second, participants were asked to **draw their symptom experiences**: ‘If endometriosis was an object, creature or animal or weather, what would it be?’. Third, participants were asked to **draw their experiences of healthcare**: ‘How would you draw your relationship with medical staff?’ After each exercise participants shared their artwork with the group, followed by group discussion of emerging views. There were three drawing tables (3 to 4 participants each) and simultaneous audio recorders at each table captured table and group discussions. Three researchers facilitated the workshop (rationale for research, DrawingOut Health methodology, drawing techniques) and took notes at each table to support the transcription process. The audio recordings were transcribed verbatim for analysis by an independent

### **Data Analysis**

Boivin and Kingwell undertook thematic qualitative analysis according to well-established methodology (see Braun and Clarke (2006). As per other DrawingOut Health workshops this was the preferred analytic approach because data collection was concluded at the time of the analysis, the data consisted of transcribed material, and there was no strong theoretical perspective driving the data description (Howitt, 2010). However, the Health Belief Model was only applied the final stages of data analysis, to interpret links between broad themes identified.

The aim of the analysis was to derive a thorough description of endometriosis as emerged during the workshop. We used a bottom-up (inductive) coding process that derives, in its first step, a set of codes that closely fits transcribed data with minimal inference-making (Braun and Clarke, 2006: 83). Briefly, the analytic process involved familiarisation with the full workshop transcript, assigning textual descriptors (i.e., codes) to all textual passages that contained relevant content, discussing the descriptors until no new codes emerged, grouping thematically related codes into more abstract higher-order clusters (i.e., categories) through similar inductive coding, and, finally, identifying overarching ideas (i.e., broad themes) from the categories and their relation to each other that expressed key findings of the data collection (Braun and Clarke, 2006: 82). The coding (codes, categories, broad themes) was discussed with the other workshop facilitators. Of the four researchers, none had experience of endometriosis, two (JB, SG) are reproductive health academics and psychologists with in-depth knowledge of the disease, one (HK) was a medical student with 2 years of clinical patient experience, and one (LER) an academic with expertise in visual and multimodal forms of communication.

In the final stage (to be completed), the booklet produced on the basis of this coding will be presented to the workshop participants, who will be asked to comment on the degree to which they feel the booklet represented their views and experiences. After agreeing the booklet and central themes a graphic designer will be commissioned to produce a booklet reflecting the broad themes using participant drawings and representative quotes. The booklet will be used to convey participants' views of endometriosis and provide a vehicle to share the results of the study. At the end of the booklet will be a brief description of the participants (anonymised) and a toolkit with infertility-related information and support for readers. Only minor changes to participants' artwork (e.g., adding colour) will be carried out, mainly to enhance coherence.

## Appendix 6 Survey of physiotherapist Questions

1. Do you at present take referrals for endometriosis patients?
2. If so, who refers them?
3. How experienced are you in the management of pelvic pain?
4. Would you be prepared to become a specialist in the management of this group of patients?

### Responses

ALL WALES WH PHYSIO PROVISION	C&V UHB	ABMU LHB	Hywel Dda UHB	POWYS	Cwm Taf UHB	BCUHB	Aneurin Bevan UHB
Number of Full Time equivalent staff working under the remit of women's / pelvic / men's health	4.5 WTE	1.76 WTE	1.2 WTE	.48 WTE	2.6 WTE	1.6 WTE 7	3 WTE
<b>Services provided</b>							
Outpatient Urogynaecology	Y	Y	Y	Y	Y	Y	Y
Chronic Pelvic Pain	Y	Y	Y	Y	N	Y	Y
Other services	vulvodinia clinic	vulvodinia clinic	N/A	-	-	vulvodinia clinic	-
What level of funding do you have at present - HR (number of physio's at what banding, number of support staff, number of administrative staff), training funds, equipment funding etc?	WTE 8,WTE 7, WTE 6 JOB SHARE, WTE 5 ROTN	1.76 WTE 7 .25 WTE 6, .64 SEC	0.5 WTE 7, 0.7 WTE 6	0.48 WTE 7	1 WTE 7, 1.4 WTE 6, 0.2 BAND 5	1.6 WTE 7	1 WTE 7, 2 WTE 6
Do you have succession planning for posts that are currently filled with members of staff due to retire in the next 3-5 years?	Y	N	N	N	Y 2-3WKS CLASS, 1-1 AX 4-8WKS	N	N
What are your waiting lists for each area?	2 OBS-8 GC WKS	8MTHS	3-20WKS	2-3 WKS	AX 4-8WKS	13 WKS	7-12 WKS
MDT	Y	Y	Y	N	N	N	Y



## Appendix 7 Financial tariff in England

See Appendix Variation in tariff in England

A relatively simple excision of endometriosis overlying the ureters costs £5272, whereas rectal shaving would attract £6128. Both procedures are usually carried out by the gynaecologist alone. Disc resection a joint colorectal procedure is £10335 and if bowel resection is required the cost rises to £10,463, increasing to £11,954 if a stoma is required.

Further detail can be found:

Complex Laparoscopic Surgery for Severe Endometriosis: Coding and Tarifs  
<https://www.bsgeonline.org.uk/downloads/Complex%20endometriosis%20surgery-%20coding%20and%20tariffs%20May13.pdf> .

Similar data has also been used in the NICE financial appraisal  
Nice endometriosis guideline Health Economics Appendix K: Pages 53 – 59)  
<https://www.nice.org.uk/guidance/ng73>

## **Appendix 8 Desirable photograph set for diagnostic laparoscopy**

**This powerpoint presentation can be viewed at :**

<https://1drv.ms/p/s!ArCfcHzNpj8mgSQvHXKdnqudkA8k>

## Appendix 9 Pain management supplement

Chronic pelvic pain is a common symptom of endometriosis and is frequently refractory to hormonal and surgical treatments. The association between endometriosis stage and severity of pelvic pain symptoms is marginal<sup>1</sup>. Women with endometriosis, have more frequent menstrual pain and incapacitation than chronic pain patients without endometriosis<sup>2</sup>.

Pain is the cardinal symptom of endometriosis in the form of dysmenorrhea (painful menstrual periods), dyspareunia (painful sex), dysuria (painful urination) and dyschezia (painful defecation).

Pain is an unpleasant subjective experience arising from the central nervous system that normally alerts and protects the body from potentially noxious stimulus<sup>3</sup>. Chronic pain, however, is pathological in itself, and often persists well after an inciting stimulus or injury has resolved<sup>4</sup>. It is a result of functional and structural rearrangements of the central nervous system that both sustain the perception of pain and facilitate its expansion to distant regions<sup>4</sup>. Given that endometriosis is a disease in which hormonally dependent, inflammatory, ectopic endometrial lesions engage the reproductive, endocrine, vascular, musculoskeletal, and neuronal systems, there are several factors that may contribute to chronic pelvic pain<sup>5</sup>.

Ongoing nociceptor activation (pain from endometriosis lesion/s) generates a bombardment of painful information into the spinal cord<sup>6</sup>. This process, in turn, induces structural and functional changes throughout the spinal cord and more rostral structures (the brain), which ultimately lead to central sensitization and evoked exaggerated responses to peripheral stimuli<sup>4</sup> (exaggerated response to pain). Furthermore, these dynamic alterations within the central circuitry can amplify and perpetuate the perception of pain long after the initiating pathology resolves<sup>4</sup> (persistent pain when endometriosis lesion is no longer there). This central facilitation manifested as a reduction in threshold (allodynia), an increase in responsiveness and prolonged aftereffects to noxious stimuli (hyperalgesia), and a receptive field expansion that enabled input from non-injured tissue to produce pain (secondary hyperalgesia)<sup>7,8</sup>. These mechanisms potentially exacerbate the pain symptoms of women suffering from endometriosis and predispose them to the development of additional pain conditions. It is of particular concern that many of the symptoms of chronic pelvic pain with Endometriosis start in adolescence or early adult life (Zondervan et al., 1999a, b; Brosens et al., 2013), a time when the central nervous system is very plastic (Blakemore and Choudhury, 2006; Kalia, 2008) and thus potentially more vulnerable to repeated episodes of pain.

## **Appendix 10 Nurse practitioner job-role specification**

Desirable skills of the Nurse Practitioner. Implementation group to convert to job description for Wales. Further information available from the BSGE endometriosis database website.

1. Knowledge skills and experience
2. Family relationships
3. Independent prescriber
4. Basic Pain management skills
5. Basic Psychosexual skills
6. Fertility
7. Hormonal manipulation
8. Diet advice
9. Basic CBT/Mindfulness
10. Nurse Sonographer
11. Nurse surgical assistant