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Introduction

Millions of women suffer from pelvic pain. The cause of this pain is often difficult to diagnose. This leads to women waiting a long time for treatment. Pelvic pain can be caused by a range of factors from ovarian cysts to pelvic inflammatory disease and endometriosis.¹ For many women, however, the cause may be Pelvic Vein Congestion Syndrome (PCS), this is a condition where varicose veins in the pelvic area bulge and cause pain.

This condition is relatively unknown amongst patients and is not particularly well understood by clinicians, including GPs and gynaecologists. The condition is not even mentioned on the NHS Choices website, for example. This has led to a situation in the UK where many women do not get properly diagnosed and live in constant pain.

Effective diagnostic and treatment options are available for women. A transvaginal duplex scan can effectively identify PCS and set women on the right treatment pathway. Following an accurate diagnosis, women can then undergo a Pelvic Vein Embolisation (PVE) procedure. This procedure involves placing very thin catheters directly into the veins and inserting a metal coil that closes the vein and stops reflux.

With there being a clear method for diagnosis and treatment of PCS, more women should get effective treatment rapidly. This report looks at the current situation in the UK and assesses how healthcare providers are currently managing patients. We also asked patients about their experiences to find out the real life impact of this condition and the way it is currently managed.

¹ NHS Choices

Key Findings

Current Management:

- Surveyed 158 NHS Acute Trusts and we found that only 48 were able to tell us how many patients had been diagnosed with PCS.
- Despite evidence to suggest that Transvaginal Duplex is the Gold Standard, 6 Trusts responded to the question on PCS diagnosis by stating that there is no agreed standard diagnostic test for PCS.
- Only 5 Trusts said they offered a specific diagnostic test for PCS.
- Only 50 out of 173 Trusts were able to provide an answer about information offered to patients regarding pain.

Patient experience:

What our survey told us:

- Patients were aged anywhere from 18 to 60+.
- The average number of diagnostics tests per patient is 4.
- Some patients received as many as 13 diagnostic tests.
- The average time to diagnosis was under 4 years.
- Several patients waited over 20 years from presenting to their GP and receiving treatment.
- Over 50% of the patients we surveyed found out about PCS online.
- On average the survey respondents had 16 GP appointments before receiving an accurate diagnosis.
What is Pelvic Vein Congestion Syndrome?

PCS is essentially varicose veins in the pelvis. It is the cause of chronic pelvic pain in approximately 13-40% of women. Varicose veins are most commonly seen in the legs and are caused by the veins becoming less elastic and no longer stopping blood from flowing backwards, causing it to pool in certain areas, leading to enlarged, bulging, knotty veins.

When this happens to the pelvic veins, visible varicose veins emerge in the pelvic region and the pressure often causes severe pain and discomfort.

The symptoms of PCS are due to the dilatation of the pelvic veins and because the blood is flowing the wrong way (i.e. backwards). The varicose veins in the pelvis surround the ovary and can also push on the bladder and rectum. This can cause the following symptoms:

- Pelvic pain or aching around the pelvis and lower abdomen
- Dragging sensation or pain in the pelvis
- Feeling of fullness in the legs
- Worsening of stress incontinence
- Worsening in the symptoms associated with irritable bowel syndrome

Pain is often the most common symptom and is usually on one side but can affect both sides. The pain is worse on standing, lifting, when you are tired, during pregnancy and during or after sexual intercourse. The veins are also affected by the menstrual cycle/hormones and therefore the pain can increase during the time of menstruation. The pain usually is improved by lying down.

How is PCS diagnosed?

Transvaginal duplex scanning (TVS) is the gold standard test for pelvic vein reflux. Research has shown that 1 in every 7 women, and 1 in 5 women who have had children, have varicose veins that come from the pelvis. Research has found that failure to identify and treat the pelvic veins that are causing leg varicose veins appears to be a major cause of why women get the veins back after receiving normal treatments elsewhere.

Venous Duplex Ultrasound scanning

Venous Duplex Ultrasound Scanning uses a technique called Doppler ultrasound to evaluate blood circulation in the veins of the arms or legs. A device called a transducer is passed lightly across different areas of your limbs, directing high-frequency sound waves (ultrasound) at superficial and deep veins. The sound waves are reflected back at frequencies that correspond to the velocity of blood flow, and are converted into audible sounds and graphic recordings.

Duplex scanning combines Doppler ultrasound with real-time ultrasound imaging of the veins. Images are displayed on a viewing monitor and may also be recorded for later examination.

It is this ability of the Duplex Ultrasound scan to actually see the flow of blood in real life that makes it such an incredibly powerful technique in the investigation of every individual patient’s varicose vein problems and in the determination of which treatment – or combination of treatments – is best for that patient.

2 BSIR  
3 Ibid  
4 http://www.ncbi.nlm.nih.gov/pubmed/23024278  
5 https://www.ncbi.nlm.nih.gov/pubmed/19470881  
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How is PCS treated?

Pelvic Vein Embolisation (PVE)

Unlike the veins of the leg, which are surrounded by subcutaneous fat, the pelvic veins have got very sensitive organs and vital structures around them. As such, using a heat producing method is not ideal - for example, a laser might end up burning the ovaries, uterus, vagina, bowel, bladder or indeed the ureters, nerves or arteries. Therefore, to be able to treat these veins successfully it is necessary to close them without using heat.

Open surgery or laparoscopic surgery is not particularly useful to treat pelvic veins. Firstly, the pain and complications from open surgery are unnecessary. Secondly, it is exceptionally difficult to reach the very small veins involved deep in the pelvis by using open surgery or laparoscopy.

By using x-ray guided venography, planned by the results of the transvaginal duplex ultrasound, very thin catheters can be placed directly into the veins that need treatment. Once the catheter is in place, a combination of foam sclerotherapy and insertion of a specialist inert metal coil can be placed into the vein, closing it and stopping the pelvic vein reflux.  

Current Situation in UK

For patients in the UK the impact of PCS can be life altering. Many women are left living in constant pain as a result of poor diagnosis and treatment. This report examines PCS and its current management in the UK. We explore how Trusts are managing the condition and how patients receive diagnosis and treatment.

We conducted research into each NHS Trust on how they manage women presenting with pelvic pain, and surveyed women who have received treatment for PCS about their experiences.

The Current Landscape

Introduction

We sent a Freedom of Information request to all 154 NHS Hospital Trusts in England to ascertain how they manage women with pelvic pain and what diagnostics tools they use to identify PCS. We asked Trusts a series of questions about how they are managing the condition around aspects such as how many women are diagnosed and how many women have been offered a diagnostic test. We followed these questions with a series of more specific questions related to diagnostic codes and the cost of treatment, such as laparoscopy.

Given that studies have shown that PCS could be responsible for chronic pain in approximately 13-40% of women, it is critical that healthcare providers are able to establish an effective pathway to manage the condition and utilise the available tools to diagnose the condition correctly. The impact of sending women for unnecessary diagnostic treatments should also be taken into account. The emotional impact of going through multiple diagnostic tests that are ultimately unsatisfactory can be devastating for patients. Poor patient pathways and multiple diagnostic tests will obviously lead to long delays in diagnosis, and ultimately treatment, which not only leaves women living in pain for longer than necessary but may also lead to their condition worsening whilst they wait.

There is also a clear cost implication for hospitals. Carrying out multiple diagnostic tests takes resources away from actually treating patients. Effective patient pathways and utilisation of the latest diagnostic tools will mean patients are treated accurately first time and avoid wasting resources that could be used to treat women effectively.

Our FOI Request

We asked the following questions:

Question 1: In each of the last three calendar years how many women a year are diagnosed with Pelvic Congestion Syndrome (PCS)?

Question 2: In each of the last three calendar years how many women have received a diagnostic test for PCS?

Question 3: On average how many diagnostic tests do women presenting with pelvic pain receive prior to formal diagnosis?

Question 4: What information is offered to women who present with pelvic pain?

Question 5: On average, how much money a year is spent on diagnostic tests for women presenting with pelvic pain?

- £311,000,000 is spent on Laparoscopy for pelvic pain each year.
- Surveyed 158 NHS Acute Trusts and we found that only 48 were able to tell us how many patients had been diagnosed with PCS.
- Despite evidence to suggest that Transvaginal Duplex is the Gold Standard, 6 Trusts responded to the question on PCS diagnosis.

9 http://www.bsir.org/patients/pelvic-venous-congestion-syndrome/
by stating that there is no agreed standard diagnostic test for PCS.

- Only 5 Trusts said they offered a specific diagnostic test for PCS.
- Only 53 out of 158 Trusts were able to provide an answer about information offered to patients regarding pain.
- We asked Trusts what information they offered to women who present with pelvic pain:
  - Only 5 Trusts said that they had a specific pelvic pain information leaflet.
  - 15 Trusts said they offered information on endometriosis.
  - 25 Trusts said they offered general information, written and/or oral.
  - 6 Trusts stated they had no information.
  - 5 Trusts said they would refer patients to the Royal College of Obstetricians and Gynaecologists green leaflet guidance.
  - 102 Trusts failed to provide an answer.
- When asked how much money is spent on diagnosing pelvic pain issues only 3 Trusts were able to provide a figure.

From our initial questions it was clear that hospitals do not track PCS, it does not have an official code and many trusts do not even offer a diagnosis test for PCS. We followed this up with a series of questions related to specific codes:

- ICD-10 code “R102” (pelvic and perineal pain)
- “N94.8” (other specified conditions associated with female genital organs and menstrual cycle)
- Code MA08Z- Major Laparoscopic or Endoscopic, Upper Genital Tract Procedures
- Code MA09Z- Intermediate Laparoscopic or Endoscopic, Upper Genital Tract Procedures
- Code MA10Z- Upper Genital Tract Laparoscopic / Endoscopic Minor Procedures

With the specific coding, 139 of the 155 Trusts surveyed were able to provide data on the total number of women that had received these procedures. Trusts were, mainly, able to provide a clear breakdown of the number of patients that had received the types of laparoscopic procedure we detailed.

We also asked Trusts to tell us the cost of individual laparoscopy procedures. Trusts reported costs between £1000 and £6000 for each individual procedure. The total cost per year of these procedures was over £311m. Finally we asked Trusts if they could tell us whether or not they have a list of symptoms that are used to decide if a patient will receive a laparoscopy. Only 8 of the 154 Trusts surveyed were able to provide a list of symptoms.

Healthcare Providers Should Support Women Better

The situation facing women suffering with PCS is bleak. There is no clear patient pathway for diagnosis or treatment. Chronic pelvic pain affects up to 15% of women and PCS is a leading cause of this. Our Freedom of Information request has identified a landscape of chaos, where women are not treated properly and are left living in pain whilst undergoing a series of ineffective diagnostic tests. Only 3% of Trusts surveyed were able to tell us how many patients had been diagnosed with PCS, meaning the remaining 97% do not properly track and monitor patients with PCS. The £311m spent on laparoscopy procedures for pelvic pain and related conditions is a clear waste of resources that could be better spent managing patients properly.

We conducted a patient survey to help us understand patients’ experience of getting diagnosis and treatment for PCS. We wanted to find out how women have been treated and their experience of treatment. We asked a range of questions about the length of time patients waited for treatment, the number of tests patients underwent, and how they heard about/found more information on PCS.

The results of our survey painted a very similar picture to the FOI request. Women were generally made to wait for several years before receiving successful treatment and underwent many unnecessary diagnostic tests that did not give a clear indication of the underlying problem.

A number of women said they had waited over ten years, some over twenty, before they received an accurate diagnosis and appropriate treatment.

Having to undergo an average of four diagnostic tests before an accurate diagnosis is made has a huge impact on patients as well as the system as a whole. For women these tests are often intrusive and unpleasant experiences. Being sent for multiple, unsuccessful diagnostic tests leads to increased pressure and stress. More accurate and quicker diagnosis should be a priority.

Studies have shown that as much as 30% of pelvic pain is caused by PCS. Transvaginal duplex is an effective diagnosis tool for PCS, by giving women this test earlier in their treatment cycle many women could avoid unnecessary diagnostic tests and get quicker diagnosis.

**What our survey told us:**
- Patients were aged anywhere from 18 to 60+.
- The average number of diagnostics test per patient is 4.
- Some patients received as many as 13 diagnostic tests.
- The average time to diagnosis was under 4 years.
- Several patients waited over 20 years from presenting to their GP and receiving treatment.
- On average the survey respondents had 13 GP appointments before diagnosis.
- Over 50% of the patients we surveyed found out about PCS online.

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What patients told us about their experiences:

Lucy: “I felt quite isolated as everything that I’ve read has pointed towards women with several kids whereas I’m still a teenager and have had no children!”

Heather: “Zero children and young - lead to me being constantly dismissed, as the rare consultants who knew about PCS associated it with children.”

Susan: “There is a complete lack of knowledge by GPs about this syndrome. GP said they had never heard of it. But didn’t seem to do much research into it. I had plenty of tests which would have shown up the syndrome but people are so unaware of it that they don’t know what to look for. Think gynaecologists need to take a much bigger role in referring people over to interventional radiologists. I would have been treated much quicker if they had.”

Patients deserve better

Women with PCS face the perfect storm of issues, lack of GP, gynaecologist and public awareness. The condition is painful and debilitating and can leave women struggling to lead normal lives. As we have seen, women face a long and difficult journey to treatment. With an average of four diagnostic tests and 51 months from when they first present to their GP to when they finally receive treatment. With some patients waiting 20 years for diagnosis and treatment, there is an urgent need for reform of the way patients are treated as well as greater awareness of the condition and its effects on women’s everyday lives.
September 2013 was when I first felt that something was not right with my body. I first noticed my tummy swelling and was very tender to touch. I noticed I needed to go to the toilet a lot more than usual and became extremely exhausted very early into the evening. To add to this, my periods had stopped.

Panic set in as I was 22 years old. All the symptoms I had were similar to those of pregnancy, although I took precautions. Over an 8 month period I received 16 pregnancy tests; blood, urine and ultrasound, of which all came back negative. My symptoms progressed; periods were sporadic if I did have them, eating habits were significantly reduced, I was having lower back pain, and sexual intercourse became extremely painful. I was at the GP surgery every week for 2 months undergoing different tests; I underwent tests for phantom pregnancy, AIDs, blood tests for inflammation as well as the pregnancy tests. All these tests came back negative.

May 2014 was when my GP referred me to a Gynaecologist, who thought it would be best to perform a laparoscopy due to my symptoms and also the fact I was on the contraceptive pill and this could mask ovarian cysts or endometriosis. In September 2014 I underwent a laparoscopy where it was discovered my left ovarian vein was an abnormal size. It was at this point that I was diagnosed with Pelvic Congestion Syndrome (PCS). It was explained that I should take the contraceptive pill for 3 months continuously to relieve pressure on the vein that was of an abnormal size.

During this period, my symptoms got worse and I had no quality of life. I had no social or sexual life. I found that as I spoke to GPs and consultants about PCS, they dismissed me because I was young and only people “who have had children” have the condition. I found it is either recognised in women who have children or dismissed because no one has heard of the condition and the symptoms were considered as part of being a women.

I went back to my GP who sent me to hospital as an outpatient for a transvaginal scan to check if there was something else that could be causing the symptoms to become more severe, however this came back negative. I was referred to a different hospital this time as it was discovered that, for PCS, an Interventional Radiologist (IR) may be able to do the procedure required. When I went to the NHS hospital, I had an MRI scan with contrast dye and it was confirmed again that I had PCS. I was scheduled into surgery for a Pelvic Vein Embolisation (PVE) the next month.

I was in surgery for the embolisation in September 2015 for over 2.5 hours where it was discovered that they could not access the veins. At this point...
I was emotional because I had put my hopes on having a quality of life back. I was advised that I would have another transvaginal scan to check it was not anything else causing the pain, and if they could find a better way of accessing the vessels. In October 2015 I went back to the NHS hospital where it was discovered that there was no reflux. This was the first time I ever heard about reflux, however the consultant was adamant that because there was no reflux and because I had not had children I couldn’t have PCS. The consultant then decided to refer me back to gynaecology. I was left feeling completely confused. Did I have PCS or was I back to square one of finding out what caused me to be in a lot of pain?

I was told in surgery about a clinic, The Whiteley Clinic, that “specialised in my condition” and I got in touch with them. I had a transvaginal scan at the clinic in November 2015 and it was discovered that I had significant reflux within 3 regions, which included a complex left ovarian vein. In January 2016 I went in for the embolisation procedure and since treatment every single symptom I was experiencing has gone and I am back to living a normal healthy life again.

I was young and had no children and felt that, because of this, I was still dismissed and felt pushed aside if someone did recognise the condition. I was made to feel like no one understood the condition and there remains a lack of knowledge and understanding of the condition.

I want to raise awareness of PCS because of this lack of awareness of the condition, not only amongst the public but by medical professionals too as I found myself explaining to my GP as well as other consultants what PCS was. I hope time to diagnosis and treatment can be significantly reduced for all patients suffering from PCS.
**Conclusion**

The findings of our report are clear – healthcare providers are not managing PCS effectively and women’s experience of treatment is abysmal as a result. This not only leads to a situation where women are suffering unnecessarily but also to a huge amount of wasted resources as patients undergo multiple diagnostic tests.

As our FOI request showed, very few hospitals or CCGs are managing PCS properly. Only 5 Trusts offered a specific test for PCS and very few were able to give clear figures on how many women are diagnosed with PCS each year. With evidence suggesting PCS could be responsible for 13-40% of pelvic pain the need to improve this situation is clear. We also found that Trusts are spending £311m on laparoscopy in this area. Better diagnosis and management of PCS could help reduce this figure, if women with PCS are diagnosed and receive treatment more quickly.

Patient experience in getting treatment for PCS has been proved woeful. Women are forced to undergo multiple diagnostic tests and wait on average four years for diagnosis and treatment. A number of women said they had over ten tests and waited twenty years for treatment. Alarmingly we found that 50% of women found information about PCS from their own research – not from their healthcare providers.

Improving understanding and awareness of PCS could support women to get quicker diagnosis. This would mean women could be released from unnecessary suffering of constant pain, and savings would made by avoiding the unnecessary diagnostic tests.

**Recommendations**

Royal College of General Practitioners, Royal College of Obstetrics and Gynaecology, the British Society of Interventional Radiology and The College of Phlebology should work together to:

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<th>Establish a joint task force for Women’s Health to look at PCS and the management of other issues.</th>
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<td>Promote awareness and understanding of PCS.</td>
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<td>Produce the necessary patient information in relation to PCS.</td>
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<td>4</td>
<td>Develop an effective patient pathway for PCS that will support all GPs to manage the condition properly.</td>
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<td>5</td>
<td>Host a joint summit on managing women’s health. This should include a discussion with patients about their experiences and how treatment could be improved.</td>
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Bibliography

1. NHS Choices – Pelvic Pain http://www.nhs.uk/conditions/pelvic-pain/Pages/Introduction.aspx Date last accessed 01.02.2017


3. Ibid.


8. The Whiteley Clinic – Pelvic Congestion Syndrome Treatment, http://www.thewhiteleyclinic.co.uk/conditions/pelvic-congestion-syndrome pcs/treatment/ Date last accessed 01.02.2017


