

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Canserau gynaeolegol](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Gynaecological Cancers](#)

GC 11

Ymateb gan: Claire O'Shea | Response from: Claire O'Shea



13th January 2023

Ref: Gynaecological cancer consultation

Dear Chair,

I am submitting evidence as an individual who at 40 years old had a diagnosis of Uterine Leiomyosarcoma (uLMS) in November 2022. The resulting treatment was a full hysterectomy in December. I am currently under the care of the Women's Cancer Centre for Wales at University Hospital Wales.

For the purposes of brevity, I have attempted to link my experiences to research and wider issues for people diagnosed with uLMS. There are many more significant issues to cover, and I would be very happy to develop these further in writing or in person, if the committee would find it useful. Uterine Leiomyosarcoma is a rare and aggressive cancer; because of this it is often diagnosed late, leading to devastating consequences. If awareness, attention and research were achieved, many cases could potentially be prevented or cured. Too many patients end up having palliative care soon after diagnosis.

Background

In July 2021 I began suffering with symptoms of Uterine Leiomyosarcoma, a rare and aggressive cancer that has a poor prognosis and a high recurrence rate. It makes up less than [2% of all cancers](#); around 5300 people a year are diagnosed in the UK. The [5-year survival rate is 50%–55% for patients with early uterine sarcoma and 8%–12% for advanced cases](#). Due to lack of awareness of this cancer by both medical professionals and people presenting with symptoms, many cases are diagnosed late; this combined with low levels of research lead to extremely poor outcomes.

Since August 2021, I have struggled to get a diagnosis and timely treatment. When I first presented with symptoms; including a lump in my abdomen, my GP diagnosed me with Irritable Bowel Syndrome, as a result of a narrow set of questions about my symptoms. This resulted in months of delay. When dealing with sarcoma, fast diagnosis is one of the most important factors in reducing mortality. [This is a common experience with Sarcoma, most GPs will only see one sarcoma in their career. The later sarcoma is diagnosed, the worse the outcomes, despite this, on average sarcomas are diagnosed when they are the size of a can of beans.](#)

Over a few months, I made several attempts to get a follow up appointment; as the medication I was prescribed wasn't working. My symptoms were developing and it became

clear to me that the lump I had been able to feel in my abdomen was located in my uterus. I was increasingly alarmed. Eventually, I insisted on seeing a woman GP having heard a discussion on research that concluded patients who were treated by women healthcare professionals had [significantly better outcomes](#). Following a consultation with the new GP, I was referred urgently to University Hospital Wales where, following scans, I was diagnosed with a suspected [fibroid](#). I had several appointments to discuss treatments and to receive hormone injections to induce chemical menopause aimed at shrinking the 'fibroid' (which was now so large it was visible protrusion from my abdomen). Following the hormone injections, I was scheduled for surgery in July 2022, however due to the 'non-urgent' nature of a fibroid and the pressures experienced by the NHS my surgery was eventually performed at the end of September 2022.

Following my surgery (open myomectomy) I was advised that I would be contacted within 3 weeks if my biopsy results showed anything of concern. After 3 weeks, I assumed I had a clean bill of health and returned to work. However, again, due to the current pressures on the Welsh NHS I didn't get my results for 6 weeks. Sadly, on the 18th November 2022, I received the results of my biopsy, which showed the fibroid was uLMS. I was immediately sent for a CAT scan to see if the disease had spread to my lungs or other areas of the abdomen. The scans showed no evidence of tumours anywhere else in my abdomen. Shortly after the scans, I underwent a full hysterectomy on the 2nd December 2022. Although there were no signs of the cancer having spread, it was vital to have the procedure as a preventative measure due to the recurrence rates.

To date, I have only had surgery, as this is the most [effective way of treating sarcoma](#). I am now under a three-monthly regime of x-rays, scans and a consultant appointment, as [recurrence rates are between 53% and 71%](#). Alongside this I am still waiting on the results of whether the cancer cells were hormone receptive, if this is the case I will need another procedure to remove my ovaries; which I was reluctant to do without establishing the histology of the cancer, due to the negative impact of early menopause.

Through my experience as summarised above and in reference to some of the specific areas the committee are interested in receiving evidence on, I consider the following evidence and information to be of particular importance.

Awareness and information

- Information and awareness are very low. [75% of people surveyed by Sarcoma UK said they didn't know what sarcoma was](#). My symptoms presented as a fibroid, an extremely common condition in women. Personally, I wasn't aware of fibroids as a condition despite considering myself to be well informed and educated on women's health. My GP misdiagnosed me with IBS due to the impact the fibroid was having on my digestive system, even with an abdominal exam where the growth was easy to feel. If I had better awareness of the condition, I would have been better able to advocate for myself, and link the developing symptoms to specific conditions.

- [40% of sarcoma patients do not receive an accurate diagnosis](#), and on average sarcoma patients wait an [average of 92 weeks](#) between spotting symptoms and being referred for investigation. This can be longer in the case of uterine sarcoma, as other soft tissue sarcomas appear in the extremities and can be more obvious due to the proximity to the surface. I waited for approximately 66 weeks, but my consultant said that was largely due to the fact I didn't carry excess weight on my abdomen and the growth was visible at an earlier stage.

Primary Care

- There were many issues with primary care, alongside the initial incorrect diagnosis. I was given blood tests at my initial consultation. When they came back as negative, I was not contacted, and had to call my GP surgery a few weeks later. I was not offered further diagnostics, despite my symptoms worsening and the medication for IBS not improving the situation. Over the phone I was simply offered a prescription for a new medication.
- I was unable to secure appointments as the econsult system my surgery has employed did not give me the opportunity to connect some of the symptoms I was experiencing together. Initially I had not recognised it as a gynaecological condition, as the main impact was on my digestive system and bladder. This often bounced me between calling my pharmacist or attending A&E depending on the pathway of symptoms. This led to frustration and giving up due to the time-consuming nature of it.
- I was made to feel like I was being neurotic. Despite being very concerned about my health, I was met with indifference at every phone call and appointment. On one occasion I called about a 'growing lump' and was told to monitor it and get in touch if I felt like it was growing. The basis of the phone call was that I already knew it was growing. It is nearly impossible to personally monitor the growth of an internal lump in an accurate way. My experience is not unique, Sarcoma UK research says [27% of patients who visited their GP were started on treatment for another condition or told that their symptoms were not serious](#).
- When I finally had an appointment with a GP, who referred me for an ultrasound, I cried with relief having finally felt my concerns were taken seriously. She was empathetic and clearly concerned, and I ended up in hospital for scans two working days later. Feeling relief at getting a standard of care that should be available as standard is also something that other women have spoken to me about.
- I do not know what my long-term prognosis is at this stage, uLMS is under researched and unpredictable. Regardless, my mental health has been severely impacted, knowing how high recurrence is, and how long it was left to grow in my body and that it was staged as aggressive as a result. My GP has not contacted me since my diagnosis or offered me support outside of the hospital treatment I have received.

Diagnostics and cancer backlogs

- [uLMS is commonly misdiagnosed as fibroids](#), as there is little to no difference when viewed on MRI or Ultrasound. Most cases of Uterine Sarcoma are discovered as a result of a routine hysterectomy or myomectomy to remove a fibroid. This was my experience and is very common as there are no reliable preoperative diagnostics. I waited from February 2022 until the end of September 2022 until I was able to have surgery. This was an additional 8/9 months where the sarcoma had an opportunity to spread and progress to Stage III.
- Fibroid surgery is considered 'non-urgent' (despite them having an enormous impact on wellbeing) and while this is understandable, without being able to differentiate between a sarcoma and a fibroid, the delay can have a catastrophic impact for women who are eventually diagnosed with uLMS (and other gynaecological sarcomas)
- Many people are offered other treatments for fibroids including uterine artery embolization. Indeed, I was offered this as the preferred treatment by my consultant. If I had taken this option the sarcoma would have been left in my body undiagnosed. Many women find themselves in this situation; [research shows that it can postpone diagnosis by an additional 13-15 months](#). While uLMS is rare, the risk and impact of sarcoma cannot be understated when women are advised on their treatment options. I opted for surgery following personal research based on the need for [more frequent reinterventions after UAE](#) and long-term studies on the women's reported wellbeing following both procedures. However, I was nervous about expressing this decision against my consultant's recommendation. She was, however, very supportive and pleased that I had undertaken research from credible sources.
- Despite the significantly better treatment I received in hospital, there were still delays and dismissal of my experiences. I had two hormone injections to put me into chemical menopause to shrink the 'fibroid' to improve the outcomes at surgery. When the hormone injections wore off, the fibroid grew back rapidly. I called the obs-gynae department 79 times over 3 days to report my concern, but the phone was not answered. I made an official complaint in writing, expressing my concerns about the rapid growth and the lack of communication about my surgery. When someone eventually called me back, I was made to feel like I was lying about the rapid growth in order to secure a surgery date (after my original slot had been missed) At no point was I able to speak to a medical professional or asked to return to clinic to establish whether my 'fibroid' had grown rapidly. My concerns were 'dealt with' by administration staff. This was another occasion when I ended up crying to an administrator about the pain and impact on my wellbeing. The rapid growth should have also been a 'red flag' and potentially my surgery should have been changed from a myomectomy to remove a fibroid, to a hysterectomy due to risk of uLMS.

Research and breakthroughs

- Most charities and professionals working on sarcoma will tell you that research and breakthroughs on sarcoma are inadequate. It is a rare cancer, and even rarer when it appears in the reproductive organs. I have had to make life changing decisions based on research with 75 participants which hasn't been updated for years. On issues like keeping my ovaries in to prevent the conditions associated with early menopause, I have had to do it with an inconclusive research base and against the advice of my medical team, who ultimately were concerned with the immediate threat to life my cancer poses, as opposed to my long-term wellbeing should I survive the current diagnosis.
- If surgery for uLMs isn't successful and the cancer spreads, research into effective chemotherapy and radiotherapy has yet to lead to a consistently-effective standardised treatment pathways So in most cases the cancer is treatable rather than curable.
- Basic research hasn't established conclusive knowledge and is widely debated. Having been diagnosed with a fibroid (a common pathway to discovering sarcoma); there isn't conclusive research to say whether fibroids [become cancerous, or whether the growth is cancerous from the start](#). This speaks volumes about the priority given to women's health. [The 5-year survival rate for testicular cancer is 95%](#) It is hard not to consider how the gap in research has led to such radically different outcomes.
- Recurrence levels are high, as is metastasis. This is both because of delays in diagnosis, but recurrence can happen many years after the primary tumour and it is not clear why this happens. With other cancers there are blood tests and other ways of monitoring, with uLMS it is visual monitoring on a 3-monthly basis, to ensure surgery can be deployed early as surgery is the most reliable method of controlling the disease.

Personal Impact

Several opportunities to diagnose me early and offer me timely treatment were missed. At the conclusion of my treatment at the end of December, the cancer cells appeared to be limited to my uterus. However, this is not reassuring. uLMS is under researched and as a result recurrence levels are high and prognosis once it has metastasized is extremely poor. It is very isolating to read about the lack of research and treatment for a condition that is likely to recur.

It is a rare cancer, but unfortunately the consequences are catastrophic. The current approach to diagnosing this condition always feels though it focuses on 'most likely; and 'best case' scenarios, to the extent that indicators of seriousness that should have set alarm bells ringing were ignored or weren't understood as significant.

I have had two major surgeries in 3 months, I am no longer able to have children, I am likely to experience early menopause and need to deal with the trauma of the last few months. I have taken significant amounts of time off work, and this will be ongoing as I am on a regime of a scan, x-ray and consultant appointment every three months for the next two years. At the two year point my scans will be done on a 6-monthly basis. I have no peace of mind and the constant looming of check-ups, means I have to plan my life accordingly and try to avoid

'scan-xiety'. I have been reassured that I will be treated with priority due to the nature of the cancer and the care provided to me by the gynae-oncology nurses and the consultant team has been personal and empathetic. I can't criticise their professionalism at all. However, due to the enormous pressure the Welsh NHS is under, I am still struggling to contact staff at University Hospital Wales to arrange appointments. I have called for results of the histology report on my cancer, and even though the original procedure was on the 30th September I do not know whether my cancer is hormone responsive - which would entail another procedure.

I live with the knowledge that due to the length of time I have had this condition and the speed at which the Welsh NHS is currently operating, my chances of dying of this cancer are high. It is hard not to feel completely isolated, as well as having my trust in the process eroded. I spend a great deal of my time thinking about the very real prospect that even with the radical surgery I have undergone at 40, the probability of me dying of this cancer still remains high.

Recommendations

Recommendations for further research and service provision can be found via charities like Sarcoma UK and Cancer Research UK. I would recommend reading their policy positions, as it will be systemic and focus on wider experiences. As a person experiencing this cancer in Wales my recommendations would include.

- Improvement of early diagnosis through primary care education; early diagnosis is key to better outcomes.
- Increased public awareness of uLMS in order that people present with symptoms much earlier.
- National Standards for Sarcoma Services were published in 2009, I have been unable to find a copy as all online links are broken, including in the [Service Specification CP149 Soft Tissue Sarcoma](#). These should be reviewed and updated with current research.
- Diagnosis of uLMS must be improved. The risks of assuming a fibroid is benign are catastrophic. All fibroid surgery should be treated with urgency if outcomes are to be improved. In order to achieve a solution, proportionate to the risk, research into pre-operative diagnosis should be funded and prioritised as a matter of urgency.
- Resources should be channelled towards general research into sarcoma. Diagnosis rates are increasing and with little understanding of the causes, it is hard to ensure rates do not continue to increase.
- There should be a cultural shift within the NHS (and wider society) into how women are treated when they present with symptoms. I was dismissed on more occasions than I care to remember. I began to refer to it as 'medical gaslighting' My worst fears were eventually realised. My experience since then has not improved and there has been little contrition or a process to educate and reform practice. My GP has yet to get in touch despite my serious diagnosis in November. Alongside a better response to women and their health concerns, primary care must have better mechanisms for learning from mistakes, which involve the patient.

I am pleased to see the attention of the committee being turned towards gynaecological cancers, it has been helpful to channel some of my experiences into this response. I hope as a result there are improvements for people experiencing the impact of gynaecological cancers in Wales.

Yours faithfully.