Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>Canserau gynaecolegol</u>

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>Gynaecological Cancers</u>

GC 18 Ymateb gan: | Response from: Judith Major



My background is ten years ago I was diagnosed with malignant melanoma, and I had excellent service from the NHS and am pleased to say that I have had all clear. My consultant at the time believed that I was just unlucky as I had not used sunbeds and was certainly not a sun worshiper and believed that it was do to with the colour of my skin (fair) and the colour of my eyes.

In July of 2021 when I had my smear the nurse believed that she could see something, and I was referred to gynecology and was to see a consultant. Due to my previous experience with cancer, I did chase up the booking office for an appointment and advised I would be available at short notice to attend a clinic. I don't believe that I waited more than four weeks but my experience at this appointment was not the best, as the consultant did not have any time to see me, so I seen another nurse who gave me an internal examination and more or less said I really don't know why you have been referred as there is nothing there.

In October of 2021 I started to experience spotting and went to see me GP, who gave me an examination and referred me as a USC and advised me that if I did not hear anything within the two weeks etc., to come back to her. Again, I chased the booking office and was told that they would potentially be able to give me an appointment after Christmas. Obviously with having had cancer previously and coming up to the Christmas period I did not want that worry, so went back to my GP who wrote a letter for me to go private.

On 4th November 2021 I was seen by a consultant at The Spire in Cardiff, who was concerned that being a USC had not had an appointment from the NHS. At this appointment I had a scan and several pipelle biopsies as my scan showed a slightly thickened endometrium with some cystic areas measuring between 6-8mm. The consultant did suggest that I have Provera for a week but was never prescribed this as no further bleeding and the biopsies were benign.

On May 17^h 2023 having not experienced any further spotting/bleeding I started to spot, therefore, I made contact with my GP. Unfortunately they could not fit me in with my GP who I had seen previously but was referred to a GP who was training at my practice. At the appointment she examined me and said that she could see blood on my cervix and advised me that she would refer me as urgent suspected cancer to the Princess of Wales Hospital. At the appointment with the GP, I asked what the waiting lists were were like and she said as it was urgent, I would be seen within the two weeks. She advised me that if I bled again or not heard anything to recontact her.

As previously since this date I have made contact with the booking office at Princess of Wales and have been told that my referral has come in, but they cannot give me a date. When have I questioned further, they are advising me that there is a waiting list and that I need to speak to my GP again to expedite the referral?

Circumstances were that I bled for around seven days in May and then no further bleeding/or spotting and will point out that at no time has the bleeding been heavy.

On Monday of this week i.e. 19th June, I started to spot and bleed again, and thought that this was unusual as it was almost like going back to having a four week period cycle. I again rang the booking office at Princess of Wales and was advised that they are at least nine weeks behind and could not advise if I would be seen in August or September and that they have been told by gynecology not to book any more appointments in as they are too busy.

Obviously, I was frustrated by this so made contact with my GP who did not install much confidence in me at all. I advised her of the bleeding that day and the situation with my appointment and she advised me that she was not aware of the waiting list and if I am honest did not seem to be concerned and the conversation then came around to the fact that as I had gone private before , she would be willing to write me a letter for a referral and that if I was in the financial position to pay then maybe it is something that I should consider not to cause me further stress.

I do believe that at this point my voice did raise an octave or two as it turned from USC to potentially me being stressed which we all know would then be about either being prescribed antidepressants or a sick/fit note.

I was really annoyed and just felt that there is lack of communication between GP practices and the NHS, and the messages are really confusing.

At 1730 hours on Monday I made a call to The Spire as after my conversation with the GP and the hospital I just felt that I had no other option and if I do have cancer, I would rather sort it early and deal with it rather than be on a waiting list with no date for referral and to be honest very little support from my GP.

I explained the situation when I rang the Spire, and I did not need a referral letter as I had been seen there previously and also of interest was that they were having more and more referrals very similar to mine where NHS GP is suggesting if you have the funds go private.

On Thursday 22nd June I was seen by a consultant gynecologist at the Spire who just happens to be a consultant with Cwm Taff Morganwg which is my health board area. I explained the situation and he was surprised that as I was a USC that I had not been seen in the two weeks and I reiterated my conversation that I had had with the booking office, and he was not aware of waiting lists nine weeks plus and was very concerned that I had been told that they are not taking any more appointments.

I had everything explained to me yesterday by the consultant and have a scan next week, where he will review at the same appointment and look at the next course of action and what may be required.

I am in a fortunate position that I can pay to go private but have to say the lack of reassurance and not knowing when I will be seen by the NHS has caused stress and at times some dark thoughts especially as I have had cancer previously,

I have always been an advocate for the NHS but feel really let down especially when Welsh Government have targets re the two-week pathway and it is apparent that no one communicates with one another so medical professionals are in my opinion giving false information.

I consider myself to be an intelligent person who has the ability to focus, ask the right questions and take the necessary action, but am really angry about the situation that I am in today, in that the NHS appears to be full of false promises and no one knows what is going on.

I feel for the women who may know be at the doctors asking for a fit/sick note and antidepressants as they are afraid of what the future holds for them and also the women who may think as they haven't had an appointment there can't be anything that serious as they would have had an appointment, therefore, could be some denial.

I know my body and I know that I have done the right thing in going to the GP as soon as the bleeding started again, so I have not ignored anything, but I think we are acutely aware that some people will deny what is going on as they are frightened until it is too late.

I don't know what my potential prognosis will be next week, but I do feel reassured after my consultation yesterday that it will be sorted if it is cancer or if it is another gynaecology issue, but it is a sad state of affairs that I see a gynaecologist from my health board area in a private clinic who is not aware of the situation within the NHS of referring people with USC.

I also note on the referral from my GP to the hospital in the Additional Relevant Information – the word Veteran – so now I wonder as I am not a young woman does this affect where they put me on a list?

I am as you would expect anxious, but I think I am more annoyed and angry at the moment that the promises given by WG, NHS are simply not being met with no communication but happy to sign someone off sick and prescribe anti-depressants which is a further cost .