

Healthwatch Birmingham's response to Women and Equalities Committee Call for Evidence: Women's reproductive health

Healthwatch Birmingham welcome the opportunity to respond to Women and Equalities Committee Call for Evidence: Women's reproductive health. Our key role is to make sure that patients, the public, service users, and carers are at the heart of service improvement in health and social care across Birmingham.

We welcome that the Women and Equalities Committee are looking into this important topic, as we have heard feedback on it from many women across Birmingham. We monitor the demographics of the people we hear feedback from, to ensure our feedback is representative of all of the communities of Birmingham.

Long waits

Women have told us about long waits for appointments, treatment and decisions to be made about their ongoing care.

This service is failing on all levels with women experiencing huge waits, I have been waiting for 15 months. Even when you do get an appointment post pandemic this is a telephone consultation and last week they DNA'd their own appointment with me. No notification from them about the missed appointment which relates to systemic issues regarding communication systems with women from this service and management of their waiting list. I noticed that I could have spent £170 and seen the same consultant 15 months ago at a private provider which speaks volumes about the two tier system that is being created. [Hospital] needs to review their current service and consult with women across the West Midlands to seek resolution of issues and ways to reduce waiting times, improve communication and work with Commissioners to get the service properly funded.

I waited nearly a year for surgery for my endometriosis and was left in extreme pain during that time. I couldn't work and ended up on morphine, just so I could cope. If I had had money to go private I could have been seen in weeks. A year wait with the specialist service was after my case was escalated and assessed as urgent.

I feel completely let down by this service and their failure to provide any service to me has had a significant impact on my quality of life. The poor communication and failure to even let me know the appointment couldn't go ahead adds another layer of stress and poor service.

I was neglected for over 2yrs. Left on an injection without monitoring which caused osteoporosis, supposed to be sent to a specialist team in London but nothing has come of it. They never return calls when voicemails are left, an open

complaint took almost a year to deal with, again I was repeatedly ignored when I tried to get in touch about it and I was forced to contact the CCG to get the hospital to reply, nothing came of the complaint and meeting we had there, the consultant sat on his phone throughout it. I don't feel I was listened too and again I've not been seen for the past 2years since.

Still waiting for treatment for stage 4 endometriosis or even a decision

I should of had a full hysterectomy as have cysts and fibroids, when they opened me up my bowel had stuck to the cyst and twisted badly, the pain was unbelievable. Doctor unravelled the bowel which has left me with bowel problems, but 6 years on the cysts and fibroids are still there and cysts have grown so waiting for treatment and scared to death cysts have stuck to bowel again which could be life threatening.

Cancellations

We have heard about the impact on women when appointments at hospitals are delayed or cancelled.

The caller made a complaint about her appointment being cancelled to the Trust around a month ago. She still has not heard back. The complaint concerns a cancelled appointment which she had been waiting for since June. This was cancelled a few days before the appointment. Another appointment has been booked for November but she is not happy. She wants her medical issue resolved and considers her treatment unfair.

They said they couldn't do an MRI scan until they saw previous scans. They've cancelled appointments without reason and didn't give me a new one. I was given the Endometriosis/gynaecology's wards secretaries number to contact and they didn't answer, they ignored my calls and told my mom to stop calling. When I eventually saw the consultant they said my growth was at risk of bursting and they said it would need an ultrasound in 2 weeks and an operation within 2 months and that was back in March, I've since been given an appointment for an ultrasound but no explanation as to what for.

Poor communication and poor attitudes from health professionals

Women told us about their experiences dealing with health professionals that communicated poorly or displayed a poor attitude towards them.

I have been a service user for many years under gynaecology. I feel the mannerism and approach of clinical staff is very insensitive. Having an illness which is of a

very sensitive nature, the approach and listening skills of consultants and lead nursing staff are appalling. I have had several operations. On two occasions the operations that I was booked for, the consultants were not even aware of what surgery I was there for. Suffering from incontinence and having lost all confidence I just got passed from consultant to consultant and got spoken to quite rudely.

I had been trying to get pregnant for 3 years and nothing was happening I had been diagnosed with PCOS when I was about 17. I was referred to get scan on my ovaries. I had a scan on my ovaries in the scan I was told I had PCOS but this wasn't in my notes. My notes stated that there was polyps in my uterus. I was sent for surgery and after waiting 12-13 hours I heard that they wanted to cancel my operation but the ward nurse told the doctor she wouldn't tell me so they decided to go ahead with my surgery. The outcome of my surgery was there was nothing inside to remove. Even though the scan had revealed there was. Since the operation I have not had a period. I was referred to fertility treatment and have chased myself today with [hospital] and they are saying they have not had my referral even though I have texts confirming it being sent.

Came for a follow up appointment. Took five minutes standing up queuing to even record I had arrived. A nurse updated the whiteboard to indicate waiting times were over an hour, but no one said at sign in, and she didn't say out loud to the room, which would have been helpful. Finally got called in to see consultant, who was very abrupt and rushed through with the appointment. He interrupted it to take a call on his mobile. He gave a lot of information very quickly, and then suggested treatment options I'd already tried, so he didn't seem to have read any of my file. He dismissed this and said I should just take it up with my GP instead. I felt very rushed and that I couldn't ask the questions I needed too. I had to sit in the reception for a while after just to regather my thoughts I'd felt so rushed.

Tried to discharge me with no feedback on surgery or what actually happened or next steps. Most staff super lovely but legit concerns about how it has got a BGSE status where you rarely get to speak to anyone that understands the basics of endometriosis. Lied to about the speciality of my surgeon when it really mattered. Would have been told nothing at all about next steps if I hadn't had to ask several times. Waste of time and pain.

No one has given me any explanation on my condition , tried to call the Hospital Clinic and GP , no written confirmation of my results or therapy other than the standard letter to attend a cervical screening. I am trying to book an appointment for a follow up and [GP surgery] being unavailable to do so. I am concerned and worried about my health and this has caused me a great amount of anxiety and emotional stress. I went privately and did my cervical screening test(Pap Test) and full gyno test, was diagnosed with Uterine fibroids and endometriosis but

again any attempt to follow up book an appointment with my GP has failed so I am unable to update my records with the NHS.

[Doctor] forgets not everyone has the level of education of health conditions or disabilities therefore when stating a condition, expects that we know exactly what it means yet fails to give an explanation or next steps. She also forgets that many people have not been exposed to gynae physical examinations being so young (early 20's), so when doing these things one should be gentle and considerate. She called me weeks later and did not complete security before disclosing information to me, only to find out it wasn't my information!! I hadn't undertaken the procedure that she stated on the phone, when telling her this, she simply said "oh, let me look again". Disgusting and insensitive behaviour. There was friction between the nurses and the Dr in the consultation room where there was an obvious back and forth verbal altercation. The nurses in the room also insensitive and held a lack of sympathy. In addition the Dr failed to read through my notes, to see I had other conditions which would make the risks of the procedure significantly higher, as a result, this is something I had to ask her if she had checked in which case she stared at me blankly and stated "so do you want me to do the procedure or not?". I went private follow the interaction with the team at [hospital] and the Gynae specialist I seen through private health care was shocked that the procedure was not carried out under anaesthetic considering my linked health conditions.

The first time I was sent here I was seen by the person who was supposed to be doing my operation, she came to see me and didn't even look at me then proceeded to throw the paperwork in my file all over the table she didn't seem to know anything about me I was then taken into theatre where I was given a general anaesthetic I woke up back on the ward and told by a nurse that the surgeon wanted to talk to me before I left and that I also had to wait for medication The nurse looking after me went for her dinner, when she came back she brought the prescription with her and was surprised that nobody had been to see me she tried to contact the surgeon by phone, phoning the operating theatre and her personal number. The nurse was apologetic and said I might as well go home. It wasn't until I attended my outpatient appointment that I found out that nothing had been done.

Lack of pain relief given for some procedures

Women also told us about their experiences of gynaecological procedures without adequate pain relief.

Whilst the consultation was really friendly and professional the procedure I had was absolutely painful. I was not offered adequate pain relief before procedure even though I informed team of what I normally had.

The reception and clinical staff were very friendly and explained why I was having a hysteroscopy and that I would feel some mild 'cramping' similar to period pain.

There was a Staff member talking to try to distract me which was at first helpful. As the procedure progressed I experienced excruciating pain worse than the contractions. I wasn't expecting the pain to be so severe that it resulted in me vomiting and passing out. I only later was informed that a biopsy had been attempted after feeling the searing pain of the implements. I do not personally hold staff accountable as they are following guidelines however I cannot understand why such an invasive procedure is carried out without the offer of anaesthesia of any description. To take internal biopsies without the option of any pain relief appears very harsh. Many women may have experienced undisclosed childhood trauma or trauma whilst giving birth and undergoing a hysteroscopy/biopsy without anaesthetic is likely to cause harm and bring up distressing memories. Patients should at the very least be told that the procedure will be very painful and have the full facts to make an informed choice. The staff were very kind and I feel that my physical reaction wasn't typical but I do feel that we should be warned about the possibilities of a feeling severe pain and likelihood of passing out and other side effects and be offered pain relief. The biopsy was abandoned so I'm still no closer to discovering if there is a problem with the endometrium.

I had to have a vaginal problem cauterised, and was offered no pain relief. I was left with severe cramps afterwards and found it hard to get home on my own. A few months later I needed a blood vessel in my nose cauterised with the same method (silver nitrate sticks) and was surprised to find I was given lots of local anaesthetic making it a painless procedure with an easy recovery. Why aren't women's private parts treated in the same way?

Was denied information and treatment options for hysteroscopy procedure. Was told G.A sedation no longer used as was deemed unnecessary. Was denied any choice available and pressured into outpatient procedure on the day.

Delays accessing primary care

We have heard from women across Birmingham who have experienced great difficulties accessing care and support from their GP practice. We have previously reported these difficulties, which showed that people with long term conditions, and people living in more deprived areas encountered more barriers to care : [People's views on access to GP services in Birmingham](#).

I have had pain in lower stomach over 2 weeks before Christmas. Finally got through for a telephone consultation. Instead I had a text to fill a form in. Then text to bring urine sample and wait two weeks for results. I was sent antibiotics as I self-diagnosed myself on the same problem as a few months ago. 7 days antibiotics have not cleared my pain. I could not believe after waiting several

weeks for an appointment it was done on my mobile phone. I am unwell in pain and disgusted with this practice.

The caller has tried to book an appointment several times since with the GP but cannot get past receptionists or get an appointment. She has tried calling the GP's secretary but the phone just rings out (30 minutes at one point) and when she again spoke to the receptionist they just said 'well she's in her office'. She has tried getting hold of the practice manager to complain and discuss the issue who is not returning her calls. Her problem, she is in a lot of pain and need a hysterectomy asap but cannot get in touch with her GP, GP's secretary or practice manager.

*They opened phone line 8.15 AM and no appointments at 8.20 AM .Ridiculous! [...]
Another day of pain!!!*

Took ages to get a Dr on the phone. Wasn't able to see GP but was sent to women's hospital gynaecology. I was asked why the Dr send me to gynae as the Dr could have seen me and given me antibiotics and painkillers. My personal view is the Dr was passing the buck.

Women told us that they had sometimes had to resort to going to A&E as they could not get help from their GP.

[...]seeing a doctor face to face is a problem. Had a problem for 48 hours and they rang me back eventually but I had already gone to the hospital as the pain had gotten worse. The next day I received a text which told me to make an appointment with the GP to discuss the results they had received from the hospital, they couldn't give me one for 2 weeks and that was over the phone.

Not easy to call them, you have to wait, you can call 20 times. Not easy to get an appointment at all. When you do get through, they give you a large window that they can call you back in, so you feel restricted and like you can't do anything. I rang them in severe pain and the receptionist told me it was not an emergency and that the GP would call me back within 4 hours. I was in that much pain I ended up going to A&E. The GP makes you feel like there is no help.

Positive experiences

Women also told us about positive experience they have had when seeking reproductive health care.

Very professional and competent staff. Good information provided all the time.

Fantastic hospital. I think it's marvellous at gynaecology, did a scan. The scan lady was lovely. I don't know why people complain.

My gynaecologist is great. Excellent explanation & support provided.

Nothing negative to say - Good care and treatment . I prefer coming here than my GP. Much more understanding.

We look forward seeing the work of the committee on this subject.

Yours Sincerely,

Sarah Walmsley

Data & Insight Officer

Healthwatch Birmingham