

Written evidence from Healthwatch Liverpool [RH0002]

About us

Healthwatch Liverpool is the independent champion for people who use health and social care services in Liverpool. We're here to make sure that those running services put people at the heart of care. One of our main purposes is to understand the needs, experiences and concerns of patients and service users and to speak out on their behalf. As part of a national network made up of local Healthwatch organisations in every local authority area of England (and Healthwatch England, the national body) our work contributes to a nationwide perspective on health and social care services.

Our evidence

Healthwatch Liverpool wants to share some of the experiences that women have reported to us since 2019 about barriers and difficulties they have experienced with gynaecological and reproductive health and the impact that this has had on their lives and wellbeing. Their experiences show how delays or inadequacies in care for these conditions can devastate people's lives leading to them living in intense daily pain with no end in sight. While they wait for care years of their lives can pass them by losing opportunities for work, social and family lives and impacting on mental as well as physical health.

The themes from their experiences are detailed below as are some anonymised examples.

- Access to services
- Administration (letters, records, results)
- Booking Appointments
- Cancellation
- Caring, kindness, respect and dignity
- Consent, choice, user involvement and being listened to
- Communication with patients; treatment explanation; verbal advice
- Cost and Funding of services
- Diagnosis
- Follow-on treatment and continuity of care
- Integration of services and communication between professionals
- Medication, prescriptions and dispensing
- Quality of treatment
- Referrals
- Staffing - levels and training
- Waiting for appointments or treatment; waiting lists.
- Waiting times- punctuality and queuing on arrival
- Concerns raised about communication and information sharing with those prone to reproductive issues due to familial history.

- Woman with familial history of endometriosis and conception difficulties learned they too have these issues and feel more could have been done to warn of the likelihood of this.

- Woman reporting removal of ovaries during vaginal hysterectomy which they did not consent to. She was only informed of this some years later at a separate medical appointment. She has experienced health issues following this surgery and now wonders if the ovarian removal could be responsible for this.

- An endometriosis patient was prescribed Prostaglandin injections and HRT whilst awaiting surgery for hysterectomy and bowel surgery. Patient was advised of delays at the trust whilst awaiting new staff and it was suggested that if they did not wish to wait they could transfer to an alternative trust which the patient accepted. The waiting list at the new Trust was significantly longer than they had expected and there was confusion/further delays over treatment and their treatment ceased causing distress.

- A young autistic patient requiring a colonoscopy under sedation experiencing delays (advised 12 months might be possible) preventing endometriosis surgery taking place.
- Conflicting information given to patient regarding IVF options due to their medical history (fibroids/endometriosis) and cost/funding of IVF treatment. Additionally, delays for IVF funding request by GP have added to the patient's distress around timescales and access.
- Patient with stage 4 endometriosis reported that they had previously had a surgery wherein a surgical error occurred and was now awaiting a further procedure. The patient was frustrated at the lack of treatment and follow-up whilst awaiting the procedure. They feel unheard when trying to discuss the situation, medications and treatments and continue to suffer mentally, physically and financially (time away from employment) whilst awaiting a further surgery. They do not accept the pandemic as the cause of these delays as they began pre-pandemic.
- Patient experienced issues with GP referring to endometriosis clinic. When referral completed, it was initially rejected due to lack of detail. Referral later accepted into general gynaecology not endometriosis clinic as required and delays for initial appointment are expected to be lengthy whilst patient experiences pain daily.
- Concerns around delays to diagnosis for endometriosis and no advice/treatment provided for symptoms whilst awaiting diagnosis. Delays also experienced for colonoscopy and fertility clinics with Covid reported as a reason for these delays.
- A patient under the miscarriage team expressed concerns about the care and treatment they have received. Following tests arranged via the consultant, they were chasing results which they eventually heard via their GP and which identified multiple reproductive health issues which they felt their consultant was not aware of and had been chasing to have a consultation about. The communication with the consultant had been poor since an initial appointment prescribing treatment, sending for scans and advising they could try to conceive. Due to previous history with miscarriages, the patient was to attend for blood tests and scans regularly but felt a burden on services and at times appointments were not known about and blood results not shared or discussed. They would have valued the consultant's input during the early stages of the pregnancy.
- Patient diagnosed with 'mild' endometriosis 7 years ago advised nothing to be concerned about and no follow up. After pleading with their GP to refer for ultrasounds due to the pain they were experiencing and the impact this had on their mental health, a new diagnosis showed ovarian cysts and endometriosis. The patient feels the delays/incorrect diagnosis have contributed to a decline in their mental health.
- Access to fertility services halted due to Covid pandemic resulting in confusion for those near the upper age limits for egg freezing/ fertility funding eligibility.
- Endometriosis patient advised of a 6 month wait for surgery because of their GP assessment. Any earlier offered date was cancelled because of the GP assessment. They have been unable to contact their GP to request this information be changed to reflect their symptoms and the impact this has on them.
- Patient diagnosed with endometriosis during A&E attendance, no treatment plan, follow-up or advice given. On approaching GP, GP was not aware of diagnosis or A&E visits wherein diagnosis took place as this information had not been shared.

- An endometriosis patient experiencing lengthy delays (2 years) for robotic surgery due to limited staff able to perform the procedure. There has also been poor communication with the patient contacting to chase the appointment date.
- A patient was diagnosed with Fibroids pre-pandemic, they had a coil fitted and were discharged from the service with no follow-up. The patient experienced a worsening of symptoms during the pandemic and difficulties accessing GP services but was placed on a waiting list to be seen but with delays likely to be 6 months. The patient is in constant pain with heavy bleeding and has considered taking their own life as a result of this.
- Patient with a small fibroid and heavy periods expressed concerns about not being listened to by the consultant or GP when they voiced that the medication was no longer working. They are also frustrated at the monitoring of the fibroid via ultrasounds as this means attending appointments far from the patients address with transport proving difficult and no course of action for the fibroid other than wait to see if this worsens whilst they continue to experience pain from this.
- Menorrhagia patient with a history of fibroids experienced delays having the hysterectomy they had been advised to have. Biopsy results had gone missing, and tests needed to be repeated. They have since experienced urinary incontinence due to the womb pushing on the bladder and have been chasing multiple services responsible for the various aspects of care needed. They also feel that due to the rarity of the condition in their age group this could be contributing towards the confusion between services with their GP writing letters to support diagnosis and chase appointments on the patient's behalf.
- Treatment for polycystic ovaries for one patient has stopped being prescribed by GP as not recommended though other treatments not suitable for this patient. The patient learned of this when collecting prescription and being told loudly by pharmacist they cannot have this medication. The patient has mental health issues and going without this medication has aggravated this further due to their appearance when not having the treatment.
- Patient finding it hard to access support groups for people with polycystic ovaries as they found only inactive ones. They felt a need for this support but couldn't find it.

We thank you for bringing your attention to this subject which has often been hidden from view leaving those patient affected feeling lost and forgotten.

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