East Suffolk and North Essex NHS Foundation Trust

Board of Directors

Report Title:	Patient Story
Executive/NED Lead:	Melissa Dowdeswell, Chief Nurse
Report author(s):	Melissa Dowdeswell, Chief Nurse
Previously considered by:	N/A

☐ **Approval** ☐ **Discussion** ☐ **Information** ☐ **Assurance**

Executive summary

Patient Story to the Board

The patient has requested to remain anonymous

SB's health journey started in 2014 when her menstrual cycle change dramatically which seemed to be overnight.

Diagnosis: Menorrhagia

Action taken by the healthcare system: For the first 2 years, the GP and a women's health specialist tried various known methods to reduce symptoms (IUD, injections, Tranexamic acid, oral contraceptives etc.).

Some methods made the symptoms worse, some gave relief, in that it stopped the constant bleeding and enabled SB to control her symptoms, so she knew when the bleeding would be and predict approximately the impact just before and especially afterwards. SB works full time and has a child living with her. Her symptoms were having a negative and significant impact on her, her family and daily life.

2015/16

SB's journey began with the hospital gynaecology department after a scan revealed a polyp and small submucosal fibroid. A female Dr was requested by SB as having a male clinician would distress her. At the appointment, the Dr explained that she believed the bleeding was caused by the fibroid and there were options to remove the fibroid. This was explained in detail, and SB felt that all her questions were answered; she left feeling informed, positive, and excited and listened to. On the day of the procedure, everything was very rushed and SB was informed that the team was very busy, but she was not to worry. They also informed SB that there would be a nurse sitting with her to distract her and support her needs during the procedure. All prepped and ready to go for the procedure, SB reports that a male nurse came and sat by her side. SB asked if it was possible for a female nurse to support her instead, but was told no. SB reported that the male nurse was very nice and kind and said he was not offended by her request for a female nurse and said that the team were very busy and could not guarantee a female nurse for procedures. SB added, that the lack of communication between staff to ensure that her preference for only female staff to be present during her procedure has had an impact in her experience of care.

2016/20

Unfortunately, SB's symptoms did not improve, SB reports that her symptoms worsened after the first procedure.

- Blood clots as big as the palm of her hand
- Having to renew her mattress 3 times over a 4 year period
- Persistent tachycardia (every week, including fainting)

- Using double sanitary protection and needing to change every 2 hours (including at night)
- Chronic Fatigue
- Severe pain
- Poor quality of life
- Impact on work due to the nature of her symptoms and the need to frequently change her clothes

A referral from the GP was sent back to the Gynaecology department, to review the journey so far to understand what could be done. SB reports that the process of reviewing this journey included the following;

- Seeing different Doctors at appointments
- Having to repeat her story and update each Doctor (only once did a Doctor have knowledge of previous medical notes and background)
- Each Doctor responding to the story with 'we can help you; there are many things we can try'.

SB reported feeling frustrated, as she had to reiterate all that had been previously suggested and tried.

A decision was reached by the clinical team in February 2018 to try a uterine ablation, which would normally be done with a local anaesthetic. SB felt that due to her previous experience and knowing that the Doctor who would carry out the procedure was male, she requested a general anaesthetic as she felt this was the only way she would be able to go ahead with the procedure and to help her mentally prepare for it. Unfortunately, during the procedure, the device did not launch. SB reports that the consultant thought he had perforated her uterus, which would trigger the safety mechanism in place for this device. SB reports that she was not advised prior to the procedure that a perforated uterus was a risk. After the procedure, SB reports that the Doctor explained how the procedure went and indicated that he would see her in a couple of months to discuss next steps. SB explained that the Doctor was happy to try the procedure again. SB then received an appointment scheduled for April 2018, however this was then cancelled shortly afterwards.

Following the cancellation of the appointment in April 2018; SB reports that;

- No appointment was re booked
- She contacted the department to be told they were 'very busy'
- She was informed that as her appointment was only a routine, they were unsure when it would be, and she was told to be patient
- She later received an appointment in September 2018 with a new Doctor
- She had to retell her story yet again, sighting previously discussed options

On meeting with the new Doctor, he yet again suggested SB try the ablation procedure again. SB explained to him that the uncertainty of an unsuccessful procedure would mean yet again another general anaesthetic, and risk no solution to her issue. SB then asked the Doctor to give her some information around the laparoscopic hysterectomy procedure as a possible option with a female Doctor, as SB does not heal well following open surgery. SB reports that she informed the Doctor that she was happy to travel to any hospital to have this done. SB explains that she was informed by the Doctor, that the only offer available to her was in the Trust, and it was an open hysterectomy.

SB reports that she questioned the Doctor's response and requested he goes to consult with a colleague to clarify the information he had given her. SB reports that the doctor returned shortly and said that his colleague had informed him that laparoscopic surgery is carried out at the Trust. The Doctor then told her she would need to wait up to a year to speak with the female Doctor who would also be able to perform a laparoscopic hysterectomy.

SB reports that no appointment was booked for her and no follow up call was made for 8 months. She reports that she received a phone call in May 2019 to attend a pre admission appointment for a full hysterectomy with no information on the type of procedure (open or laparoscopic). On the phone call, SB explained that she really would like to discuss the booked procedure with a Doctor before committing to such major surgery as she had a cardiac ablation in March 2019. The person on the phone informed SB that someone would be in contact over the misunderstanding and poor communication.

SB explained that she had no contact or appointment made and so she resulted to call the department

on numerous occasions in June 2019. SB was informed that she would need to see her GP to get a re-referral, as she had not attended her surgery. SB requested to speak to a service manager and explained the situation to them. The service manager went ahead and organised an appointment.

SB reports to receive

- An appointment with a Female Doctor for July 2019

At the appointment, the Doctor recommended to try ablation again as it was highly possible that it would work and that if it did not work, then a hysterectomy would be booked.

SB reports that the procedure was then scheduled for 4th March 2020. On the day of the procedure, SB arrived and was seen by a new male Doctor who explained that he was unable to complete the procedure, as there had been no recent investigation for over 3 years, which he would need before commencing. SB explained that the Doctor identified there had been no recent scans or test, and he said he would carry out a laparoscopy examination immediately, to see what the results were and discuss next steps. SB further explained that in light of the results from the laparoscopic examination, a scan was booked and she was directed back to the female doctor who recommended the ablation procedure in July 2019.

SB reports that after attending the scan appointment there was once again no communication with her as to next steps. SB explained that due to lockdown as a result of COVID19 pandemic, she was unable to attend her appointment scheduled for 23rd March 2020 as the department had cancelled it.

SB explained that on 4th May 2020, she contacted PALS as she had received a letter detailing the results of her scan and recommended procedures from the Gynaecology department. SB reports that she was not consulted on the recommended procedure and felt that the decision of her care was not done with her involvement. SB reports that she tried calling the department to seek clarity however, the telephone number on the letter she received was incorrect. SB reports that PALS forwarded on her request to the gynaecology service manager to escalate her concerns.

SB reports that on 15th May 2020, the Doctor who had originally attempted the first ablation in February 2018 called her to discuss next steps. SB felt that the Doctor actively listened realised that SB's clinical notes did not reflect her journey. SB and the Doctor reached a decision on a way forward and a hysterectomy was scheduled and performed in July 2020.

Experience of care

'What worked well for me'
Service manager was professional, empathetic and realistic to time frames and needs of both patient and hospital
Staff were caring and hardworking
Some members of staff supported others when they found that communication with me was inadequate
My discharge and aftercare was efficient
I had the ability to share my lived experience. This made me feel that I was truly listened to and valued
I received adequate support from the hospital staff
I felt safe during my stay in hospital over COVID
I felt ward staff were outstanding regarding COVID guidelines; they respected my needs, ensuring that they communicated efficiently and understood my needs; using expressional words to show what I couldn't see behind the mask

'What didn't work so well for me'
Lack of adequate communication throughout my journey
Lack of consistency of professionals to ensure my story does not have to be re-told
Lack of understanding of the impact of symptoms on my health and wellbeing
Lack of active listening from professionals
Lack of respect for my needs with regards to ensuring female staff carry out my procedure
Lack of understanding of the impact of using the word 'BUSY' and how it made me feel

Main Message
There is need for a more robust system enabling effective communication when patients are likely to see different clinicians within their journey. A document that captures 'what matters to you today', could be helpful in improving the patient experience and this could be completed whilst the patient is waiting to see the clinician and used to enable conversations during the consultation.

Whilst honesty and transparency is valued, the use of certain words like 'BUSY' can change how a patient feels, behaves or communicates with staff. Staff should consider using words that reflect empathy and compassion.

The system which highlights patients who find themselves with cancelled appointments or delays, needs to be effective so that patients are regularly kept updated; facilitating alternative routes of seeing a clinician instead of putting them back on standardised waiting lists for treatments especially in cases where cancelled appointments and delays are due to departmental errors.

Effectively communicate with patients on the realities of waiting times to better manage their expectations.

Staff should use alternative words to encourage patients to give feedback if they are dissatisfied with the service rather than suggest the patient, 'makes a complaint'. This can have a negative impact on the patient journey, especially if all that was needed was to give feedback to let someone know how they made them feel.

Having the opportunity not only to talk about my experience, but to share it and be asked to get involved to support the hospital allows patients to know that the hospital is listening and welcomes feedback.

Action Required of the Board/Committee
The Board is asked to reflect and learn from the patient and their loved ones experience.

Link to Strategic Objectives (SO)		**Please tick**
SO1	Keep people in control of their health	☑
SO2	Lead the integration of care	☐
SO3	Develop our centres of excellence	☑
SO4	Support and develop our staff	☑
SO4	Drive technology enabled care	☑

Risk Implications for the Trust *(including any clinical and financial consequences)*	Nil reported
Trust Risk Appetite	Quality: The board will take minimal risks when it comes to patient safety, patient experience or clinical outcomes. Its tolerance for risk taking will be limited to decisions where the impact is low and the potential mitigations are strong.
Legal and regulatory implications *(including links to CQC outcomes, Monitor, inspections, audits, etc)*	Operating in line with NHS E patient experience framework
Financial Implications	Nil
Equality and Diversity	In line with national and trust policy, in order to treat patients holistically and as individuals.