

REPORT TO THE BOARD OF DIRECTORS (BoD)

Report title: Patient Story for the Board

Meeting date: 5 June 2025

Board sponsor: Chief Nursing and Midwifery Officer (CNMO)

Paper Author: Lead for Patient Voice and Involvement

Appendices:

Appendix 1: Patient Story

Executive summary:

Action required:	Information
Purpose of the Report:	To hear the story of a patient who was diagnosed with breast cancer at 23 and treated at Queen Elizabeth the Queen Mother Hospital (QEQM). It highlights a number of positive learning points for the Trust.
Summary of key issues:	<p>East Kent Hospitals University Foundation Trust (EKHUFT) diagnosed and treated a young woman who shared the following observations about her treatment:</p> <ul style="list-style-type: none"> • Using a holistic approach to provide compassionate care; • The importance of having a tailored and flexible approach when discussing a diagnosis with patients; • The value of Cancer Nurse Specialists in a patient's treatment; and • Positive feedback about Viking Ward (QEQM).
Key recommendations:	<p>The Board of Directors is asked to NOTE:</p> <ul style="list-style-type: none"> • The service and teams involved in R's care demonstrated compassion and live the Trust's values; • Modelling compassionate leadership at a consultant level supports compassionate care in the wider patient journey; and • Flexibility in care planning and treatment plans that will benefit the patient, by improving their experience and outcomes.

Implications:

Links to Strategic Theme:	<ul style="list-style-type: none"> • Quality and Safety • Patients
Link to the Trust Risk Register:	None



Resource:	No
Legal and regulatory:	The Trust has a duty to comply with the Equality Act 2010, including making reasonable adjustments for disabled people.
Subsidiary:	No

Assurance route:

Previously considered by: Not applicable - Patient/family stories come direct to the BoD.



PATIENT EXPERIENCE STORY

1. Purpose of the report

- 1.1 The report provides background for the patient story that will be heard at the Board of Directors (BoD) meeting. The story relates to a woman, R, who was diagnosed with breast cancer at 23 and treated at Queen Elizabeth the Queen Mother Hospital (QEQM). It highlights a number of positive learning points for the Trust.
- 1.2 These learning points include wait times for treatment, communication between staff and with patients and delivering tailored, compassionate care. R will attend the BoD meeting to talk about her story and the impact it had on her wellbeing and how the experience has influenced her view of the care available in East Kent.

2. Background

- 2.1 R is a 23-year-old female who was diagnosed with breast cancer two years ago.
- 2.2 R found a lump which was painful but attributed it to cyclical breast pain and also had heard that 'if it hurts, it's not cancer'. She became concerned when it did not subside so went to her GP who referred her for an ultrasound and a biopsy.
- 2.3 R was diagnosed the following week. Her diagnosis appointment had been moved forward by the team at QEQM which is now appreciated. She was advised that she could bring someone with her, and on reflection would suggest that we communicate that people *should* bring someone with them, if they can. When she was given the news that she had cancer by a consultant accompanied by three nurses, it felt "like everything went into a vacuum...I just said, yes". The team understood that R was not feeling ready to take detailed information in, so encouraged her to sit in the café and call her mother, who came to the hospital and attended the rest of the appointment with her.
- 2.4 At the diagnosis appointment, the team had asked a lot of personal questions to identify R's support network and wellbeing. This felt indicative of the fact she was receiving a serious diagnosis but R feels it was the correct approach. The day after diagnosis, a lot of leaflets containing information about cancer arrived which was upsetting. Due to R's age, steps were taken to arrange for oocyte cryopreservation (extracting and storing a woman's eggs).
- 2.5 The following week consisted of many more appointments but was also when Ami Archer, Teenage Cancer Trust Teenagers and Young Adults (TYA) Clinical Liaison Nurse Specialist, was introduced to R.
- 2.6 R was becoming frightened, particularly around the need to have an operation under sedation for the oocyte cryopreservation. Ami talked to her about every aspect of her wellbeing and supported her when she was upset during a blood test. Ami encouraged R to talk about things that were not in her comfort zone, so she was better prepared for the treatment she was soon to receive. The fact that the treatment was explained clearly was ultimately very reassuring for R. She describes Ami as a 'saving grace'.
- 2.7 Chemotherapy was started a few days after the oocyte cryopreservation operation. R describes chemotherapy as "like hell...it's a poison and it feels like it". She had been prepared for the symptoms of nausea, loss of appetite, broken fingernails and increased sensitivity to water temperatures but it was a very difficult experience. A week and a half after the first chemotherapy, R began to lose her hair.

- 2.8 During chemotherapy, R had regular appointments with her Oncologist who was calm and kind. R's experience of having an induced menopause was also very difficult and her mental health suffered as a result. She kept telling herself – “this is just the hormones”.
- 2.9 After chemotherapy, surgery was completed and then a second surgery was required as the cancer had spread into R's lymph nodes. Radiotherapy followed, then low dose chemotherapy which finished in June 2024.
- 2.10 R's treatment lasted 18 months. She accessed counselling and found it useful and feels that “the journey starts after (the treatment) has finished”. As well as being supported by the teams at QEQM during and post-treatment, R also accessed support from a number of local and national organisations in the community.
- 2.11 As well as treating R as quickly as possible from her first contact with the hospital and communicating effectively with her during the initial diagnosis, the way that staff cared for R is a regular observation in her story. She describes the team on Viking Ward as “kind, understanding – I got a chest infection and needed a drip so they brought me fudge cake and ice cream. I felt spoilt rotten...Everything was amazing. The treatment is so horrible but I couldn't fault (the team) for it and they made it all much better than it could have been”.
- 2.12 The above experience illustrates how compassion and kindness can make treatment manageable and how by acting according to Trust values and standards, patients can be better supported through unexpected challenges. Administrative focus on seeing patients rapidly combined effectively with a tailored and personalised treatment plan that all of the teams involved contributed to, in particular Ami (R's Nurse Specialist). Compassionate and dignified care is within the gift and responsibility of all our staff and can have a positive impact on a patient's wellbeing.

3. Conclusion

- 3.1 R's story highlights the importance of compassion, good and regular communication and a holistic approach that are wider reaching than just cancer services. Flexibility around how a patient is given important information and a person-centred approach to treatment has in this case resulted in a very positive story, told by a brave patient.
- 3.2 The BoD are asked to **NOTE**:
- The service and teams involved in R's care demonstrated compassion and live the Trust's values.
 - Modelling compassionate leadership at a consultant level supports compassionate care in the wider patient journey.
 - Flexibility in care planning and treatment plans that will benefit the patient, by improving their experience and outcomes.