

**EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST**

REPORT TO:	<b>COUNCIL OF GOVERNORS – 9 MAY 2014</b>
SUBJECT:	<b>PATIENT STORY</b>
REPORT FROM:	<b>CHIEF NURSE AND DIRECTOR OF QUALITY &amp; OPERATIONS</b>
PURPOSE:	<b>FOR INFORMATION AND DISCUSSION</b>

**CONTEXT/REVIEW HISTORY**

The Board of Directors have been using patient stories to understand from the perspective of a patient and/or a carer about the experiences of using our services.

Patient stories are a key feature of our ambition to revolutionise patient and customer experience. Capturing and triangulating intelligence pertaining to patient and carer experience from a variety of different sources will enable us to better understand the experiences of those who use our services.

Patient stories provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

**SUMMARY:**

This month's story is presented at the request of the family involved. It is the story of a 79 year old lady who presented with a mass in her abdomen. It describes a long protracted journey through many different specialties and disciplines. It reveals a picture of silo working; avoidable delays; miscommunication and aspects of poor basic care. These are described as:

- A delay in the 62-day cancer pathway that took 87 days;
- Delays in the patient having her investigations;
- An essential referral to the surgical team not followed through;
- A delay in her diagnosis;
- Poor discharge processes;
- A failure to inform other agencies of her death causing upset and distress for the family when correspondence and items of equipment continued to arrive.

It shows how simple things not being communicated appropriately can lead to serious consequences for the patient and an upsetting experience for the family. A number of lessons were learned from this patient's experience and by collaborating with the family a multidisciplinary cross Divisional action plan has been agreed that addresses the issues raised from the investigation and aims to prevent a similar experience occurring for someone else.

**Board of Directors  
Patient Experience Story  
March 2014**

**Introduction**

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**The Patient Story**

This story is written by the patient's daughter. It is about a 79 year old lady, Mrs M, with a suspected diagnosis of cancer.

*On 17<sup>th</sup> July, my mother went to see her GP because she had been suffering various symptoms including tiredness; loss of appetite and dramatic weight loss; diarrhoea and stomach pains. Shortly after this, she received an appointment for a consultation at the William Harvey Hospital. We saw the Doctor on 29<sup>th</sup> July, and received a copy of his letter to Mum's GP detailing his findings. It was apparent from this that Mum had been referred to the hospital via a "rapid access proforma". The Consultant stated that he had arranged for Mum 'to have an urgent colonoscopy and CT scan of the chest, abdomen and pelvis' following the discovery of a 3x3 cm mass in her left iliac fossa. The CT scan was carried out on August 7<sup>th</sup>, and the colonoscopy on 18<sup>th</sup>. Throughout all this time, Mum was becoming steadily weaker, the diarrhoea and abdominal pain worse. I'm sure you can also imagine the psychological torment she was experiencing because of the uncertainty of what's wrong with her. At this time, we were sure that everything would be quickly resolved because her case was obviously urgent.*

*The Doctor who performed the colonoscopy gave us a copy of his report, which advised that Mum have a CT led biopsy of the tumour. He recommended that we telephone the consultant on the following Tuesday to find out if an appointment had been made for this. When I rang, I was told that the Consultant we had seen at the hospital had left at short notice but that his cases were now being dealt with another Consultant. Mum then received an appointment to see him, but not until 27<sup>th</sup> August. This Consultant confirmed that Mum had a tumour that needed to be removed, whether malignant or not. However it was necessary to carry out the biopsy first, even though this may not be conclusive. He said he'd already arranged this and an appointment would come through shortly. As we'd heard nothing a week later, I telephoned his secretary. She said she'd investigate and call back. When she did so, she gave us the Radiology Department's telephone number and said they would be able to help us. When I eventually got to speak to someone there, I was told to call back in a week, as even "urgent" referrals take two weeks. I subsequently rang again on 10<sup>th</sup> September. I was told that the lady I needed was dealing with someone else and would call me back shortly. The call never came. Mum's GP then made a home visit to Mum on Thursday 12<sup>th</sup> September. He was appalled at the delays and promised to see what he could do. His secretary telephoned shortly after his return and confirmed Mum had an appointment for the biopsy on 20<sup>th</sup> September. This was almost 5 weeks since the colonoscopy.*

*Mum had the biopsy on 20<sup>th</sup>, at which the Doctor again stressed that this may not show conclusively what is wrong with her. We were then hoping that at least with the results of this procedure, Mum would get an appointment through to discuss the findings, then an operation could be planned. It was therefore a huge disappointment for Mum to receive a phone call on 30<sup>th</sup> September asking her to come in for another CT scan on 2<sup>nd</sup> October. She had this done, but then on 3<sup>rd</sup> October she received a letter with an appointment for an MRI scan on 13<sup>th</sup> October! Whilst we appreciate that the Health Service is carrying out tests in Mum's best interests, why did it take so long? We cannot believe that 12 weeks had gone by since Mum visited her GP and we STILL did not know what was actually wrong with her. This is surely unacceptable for anyone, but for a lady of her advanced years, it was absolute torture. The worst thing was, that if it turned out to be something that should have been operated on, but was now too late, will the Health Service accept responsibility for their failure to act in a timely manner? I somehow doubt it!*

The family felt that they were watching their mother deteriorate and that results went from one person to another in the organisation. This caused them immense worry and stress. Indeed, despite the national standard being 62 days to start treatment, this patient was on day 87 before there was a confirmed diagnosis. Further scrutiny showed that her colonoscopy had been undertaken 10 days later than it should have been and that the CT guided biopsy was also delayed. Unfortunately these delays were not escalated through the Multidisciplinary Meetings (MDM) or the weekly Patient Tracking List (PTL) meetings where all cancer patients are discussed. The Radiology team also confirmed that they had capacity issues which added to the delays. The family were left making phone call after phone call. Their faith in the health service was dwindling to such an extent that the son took a urine sample to give to the GP himself as he felt that if he left it with the receptionist it would get discarded.

On Wednesday October 9th 2013 this lady was admitted to the Clinical Decision Unit (CDU) at William Harvey Hospital where she stayed for a week. She was passing faeces in her urine and had diarrhoea. Whilst in CDU, she was reviewed by the medical team who said they would speak with the surgical registrar for a review. This review did not take place. The hospital systems do not 'flag' up cancer patients for the teams to be aware of. The documented plan was to send the patient home when her diarrhoea stopped. This patient remained under the care of the Stroke Consultant instead of being seen and her taken over by the surgical team.

Prior to discharge home and in preparation for this, Mrs M was referred to the Occupational Therapists and Physiotherapists. There was a delay of 24 hours before the Physiotherapist was able to make her assessment. Mrs M was discharged home on 15<sup>th</sup> October 2013. The family felt that they were left to cope with their mother alone at home without support and that they were unable to leave her.

On Monday 24<sup>th</sup> October 2013 Mrs M was readmitted at 5 am when she was seen by the surgeons following a referral from A&E. Theatre was booked for her at 1pm. The family felt that during the morning their mother's pain was not well controlled, she was frail at less than 6 stone and the mass had grown. She was diagnosed with a perforated bladder and died post operatively in the Intensive Care Unit later that day. The family shared stories of receiving appointment letters after she had died. Other professionals had arrived at the house to make bathroom adjustments and give a pressure relieving mattress. The son had to telephone the hospital and leave a message to stop these events.

Since these events, the family have met with the surgical, medical and nursing teams involved. Below are some quotations about how they were feeling:

*'It has been delay after delay and when she came into CDU we thought at least she was in the best place and they would sort her out'.*

*'All it would have taken is a phone call'.*

*'They had her in the wheelchair by an open door in just her pyjamas. I went back to get her dressing gown because she was shivering'.*

*'All Mum was concerned about was us tending to our children and getting to the toilet. It just seemed everything was getting worse. The evening she was discharged, we got home and the morphine was missing. We just thought, 'what else'?*

*'I wanted to come and see Mum after she had died to make sure you had the right person. We should not have been made to feel like that. It was only when the undertaker brought the ring round that we knew we had the right person. I spoke to Becky in HDU about getting Mum's ring and she was lovely. To be in a position where you could not even be sure the hospital had the right body is terrible'.*

### **Summary**

This story describes a multitude of delays in the care of a cancer patient. The delays were evident during the initial pathway to confirming her diagnosis, and due to her investigations not being organised as per the cancer standards. There was a failure to escalate these delays through the existing structures and a failure to see through a referral made to the surgical teams.

Actions in place to address that were agreed with the family to address these issues are progressing. These comprise:

- Presentation of Mrs M's timeline for MDM discussion and reflection - This action has taken place and the teams have discussed this case in detail reflecting on where care could have been improved.
- Review the length of time for diagnostic colonoscopy and CT biopsy - Meetings are in progress with the Radiology and Pathology teams to explore ways to prevent delays in the pathway for future patients. This case occurred during the problematic implementation of the GE RIS which may have had an impact. However, with regard to histology, there are fast track mechanisms in place. Communications are in progress between Pathology, Diagnostics and Radiology to reinvigorate the time frames we work to and should be managing when a patient is on a cancer pathway. In addition, discussions are also in progress to streamline the pathway further by referring the patient straight to diagnostic testing so that we can omit the first OPD appointment thereby shortening the pathway.
- Review why the delays were not escalated at the PTL meetings - The Deputy Divisional Director for the Surgical Division is meeting with each operational manager and the cancer co-coordinator from each tumour site to describe their joint responsibility. The escalation flow has also been revised.
- Explore whether there can be a flag on the Patient Administration System for cancer patients - This has been explored and the flag on PAS is possible under the existing system we have. We can add a known cancer patient and

state on PAS “please contact cancer surgeon in charge of care”. In order to have this instigated, permission from the cancer leads is required, so the item will be part of the next Cancer Board agenda. Once completed, this link can ensure the teams are bleeped or contacted.

- Review multi-professional working – this action is in progress and formed part of the discussion at the MDM.
- Occupational therapy delivering equipment after being notified Mrs M had died – this action is in progress, and an update is awaited.
- Review why there was not a key worker available in the outpatient appointments – this action refers to the nurse from clinic not attending. This is being investigated.

In the meantime the family have met with the medical and surgical teams, Consultants and Management teams and the Ward Manager involved. They were very keen for the Board of Directors to hear their story in order to make improvements and prevent a similar experience occurring for someone else. The Deputy Divisional Director for the Surgical Division is updating the family of progress against these agreed actions.