Using patient knowledge and experience to support service development

Suzie Shepherd
Lay chair, Royal College of Physicians Patient and Carer Network
The luck of the draw

A patient’s perspective of acute medical care
An acute care patient journey – from primary to secondary care and back again.

Day one of twenty six days:

- The patient, a known SLE sufferer calls her GP out, she is complaining of abdominal pain and diarrhea, the patient is immunosuppressed and has a fever
- The family GP does a home visit.
- The symptoms continue for a further three days, the patient calls the GP again, who explains that there are some nasty stomach bugs going around and if she starts to pass any blood to call the surgery.
- By day five the patient is in severe pain, passing blood and dehydrated, she calls the surgery and a GP calls her back. The GP explains that she needs to go to the hospital and that the practice will call an ambulance and do a letter and fax it through to the medical assessment ward to avoid a long Accident and Emergency department wait.
The first hiccup

• The ambulance does not arrive.

• The patient calls the ambulance service and they are told ‘GP calls for an ambulance are not a priority, if the patient needs acute care 999 should be called’

• This halts the emergency admission until the GP calls the ambulance service.

• The ambulance arrives three hours after the GP spoke to them following a further call from the patients GP. The medical assessment unit are waiting for her
The second hiccup

- The ambulance staff refuse to take the patient to the medical assessment unit.

- Accident and emergency know nothing about her.

- At this point the patient is left in the waiting room.

- Thankfully a nurse notices and speaks to the patient.

- Patient is taken to the medical assessment unit.
The acute assessment begins

- The patient is swiftly admitted to the medical unit
- The unit has her medical history, prescription chart, reason for admission
- The registrar on duty has already spoken to her rheumatologist
- Pain relief and a drip are set up, samples are taken for lab tests and a catheter is fitted, there is blood and protein in the urine sample
  - The lab results are returned very quickly
The acute assessment begins cont....

• Having looked at the results the registrar arranges for the patient to be moved to the acute surgical assessment unit.

• Even though it is a bank holiday the surgeon cycles in to the hospital and orders a CT scan and biopsies to be taken.

• The CT scan and the results are done on the same day, they show severe pan inflammation of the colon, a biopsy needs to be done before any treatment is started.

• The patient is to have daily x-rays and the biopsies are arranged for the bank holiday afternoon. There are no further renal investigations undertaken.
The third hiccup

- The registrar requests a biopsy pack.
- It is a bank holiday there aren’t any sterile biopsy packs available.
- The patient’s health is deteriorating. The patient has severe abdominal pain and her temperature is increasing.
- The surgeon decides to observe the patient for a few days, after starting a steroid drip.
- The patient is moved to the surgical ward two days later.(PAST MIDNIGHT)
- The patient remains on the surgical ward for a week, during which time the biopsies and a colonoscopy are performed.
- After looking at the results the patient is referred to the IBD team who consult with her rheumatologist, but not her renal specialist.
The fourth hiccup

• There is no bed on the IBD ward, a rheumatology ward is not considered even though there is a multi disciplinary SLE team that includes the patients renal specialist.

• The patient is still catheterised.

• The patient is moved to a general ward.

• After twenty four hours a bed on the IBD ward becomes available.

• The patient is moved, after midnight again.
The journey's end

• For a further seven days the patient is observed on the IBD ward.

• In addition to her usual medication she is given steroids orally and pain relief continued.

• The biopsy results show IBD but cannot give a specific diagnosis as treatment was started before the diagnostics could be done owing to the bank holiday.

• On day twenty six the patient is discharged and is to continue treatment at home.

• There is a question about whether the patient suffered from SLE vasculitis or IBD.

• There is no discharge planning and the letter to the GP that the ward sister produced is inaccurate.

• The patient is returned to the care of her GP and remains on steroid treatment for a further six months, under two weekly review on the IBD outpatient clinic.
Lessons learnt – from a patient’s perspective

- Patients need educating

- Acute medical patients should be fast tracked avoiding A&E.
- The medical assessment unit is wonderful

- Ambulance staff and A&E do not always understand the needs of the comorbid patient. There is a need to educate.

- The GP can communicate directly with the AMU who are then fully aware of the patients problem and medical history.

- Communications and systems within the ambulance service and between hospital specialists need to change.

- Had it been out of hours when the patient first needed a GP they would not have had appropriate access.

- There is a lack of clinical freedom and leadership
Lessons learnt – from a patient’s perspective

• There is a lack of resources available in out of hours services.

• Where treatment needs to be started quickly, poor access to diagnostics can affect results, making diagnosis difficult.

• Specialists will do their best to see the patient during out of hours time, but the system relies on a lot of good will. The systems do not support this.

• The service is there but the equipment is not.

• The bed booking system does not meet the needs of the patient.

• There is a need to improve ward round, handover and discharge.

• Primary Care does not understand what the LTC patient needs.
The patient’s role in educating the system

• If patients were able to use their journey as case studies the system and staff could learn and improve services more quickly to meet the needs of the patient.

• Lay Patient involvement in developing strategy is key to getting things right.

• For patients who suffer from Long Term Conditions a card should be developed that details a summary record and who the patients specialists are.

• Long term condition patients should be red flagged through the system to the appropriate team.

• The system needs to learn to trust what patients say about their condition and how it affects them.