healthwatch Tower Hamlets

Case study- pain management in the Royal London Hospital

Detailed feedback we have received from one patient prompted us to examine patient experience with **pain management in the Royal London Hospital.**

We have identified **48 individual comments** from Royal London Hospital patients on the topic of pain management (26 received in 2017 and 22 in 2018). Patient opinion of pain management in the hospital is **broadly negative, but might be improving**, particularly in the Maternity department.

The Maternity and A&E departments receive the most feedback on pain management, but the pain team, surgical clinic and fracture clinic see a higher proportion of negative comments. **Patients under the care of the pain team are concerned about communication in the department** (both among medical professionals and with patients); in some cases, it has been unclear which patients the pain team does or does not deal with.

Overall, multiple patients feel that **their symptoms are dismissed by medical professionals**; in some cases, they receive only over the counter painkillers, without any further investigation or explanation about their condition, despite being in severe pain; they receive inadequate low doses of painkiller or are discharged from hospital while still in a poor state.

This case study highlights the need for further investigation in the following areas:

- **Communication between the pain team and medical professionals from other departments.**
- **Communication between doctors and patients on the subject of managing pain (including around safe dosages of various painkillers).**
- **Delays in receiving pain relief for hospital inpatients.**
- **Admin, planning and staffing issues that could impact upon availability of pain relief for hospital inpatients.**

A wider research project touching upon these topics would be needed in order to assess accurately the scope of the issue and produce recommendations for tackling it.

A series of **Healthwatch Enter and View visits focused on the topic of pain relief** could be a starting point for such a project.

The detailed cases

An inpatient's story

In August 2018 we have received extensive feedback from "Grace" (name changed), a patient treated in the Royal London Hospital Emergency Gynaecology Unit. She suffered from a condition causing severe pain and she was strongly dissatisfied with the level of support provided to her for managing it.

Grace had very deep veins, which meant she needed to be cannulated by an anaesthetist under ultrasound guide and was intolerant to oral (including soluble paracetamol) but could tolerate it intravenously. This information, as well as a full least of medications for pain management prescribed by her regular consultant, has been conveyed upon admission to the ward manager and ward sister.

However, from the beginning, she received lower dosages than those prescribed, which were insufficient, to the extent that her continued pain and nausea prevented her from eating. She states that the Pain Team were unwilling to deal with her case, as they found it too complex.

Grace's regular consultant only saw her once, and prescribed intravenous paracetamol, as well as buscopane, to be administrated through a cannula, and referred her to the anaesthetist. Said anaesthetist only showed up after 10 pm in the evening and unsuccessfully attempted to cannulate Grace (the cannula broke because of rough handling by a nurse). A referral for a new cannula was not put in place promptly, causing Grace to remain in severe pain, without her prescribed treatment, over an entire weekend.

A different consultant saw Grace on Sunday evening, and wrongly noted that she was allergic to paracetamol; which Grace promptly corrected. However, when she was cannulated on Monday, Grace found that the intravenous paracetamol has been removed from her prescription list, possibly because of the misunderstanding with the consultant. A nurse later explained to Grace that the Pain Team (whom were not, to her knowledge, involved in her care at the time) had ordered she can have only oral paracetamol (which she was intolerant to) but not intravenous). Until her discharge several days later, Grace has been unable to see her usual consultant or to have her prescription list corrected.

Her case draws attention to a number of issues in regard to the care patients like her receive in hospital, primarily around:

- Communication between patients and medical professionals.
- Communication between different medical professionals: ex- the pain team and specialist consultants.
- The support provided to complex cases.
- The importance given to treating severe pain in the absence of more visible symptoms.
- Administration and planning in the hospital.

Throughout her hospital stay, Grace felt that her severe pain was not taken seriously by doctors and nurses, that the severity of her symptoms was consistently underestimated and that she was unable to communicate about her needs or to make informed choices.

An outpatient's story

"George" (name changed) suffers from long term chronic pain caused by arthritis. In order to manage his pain, he uses Fentanyl patches, as well as tramadol and paracetamol. Fentanyl can currently only be prescribed by a consultant from the Pain Team at the Royal London. The process of getting an appointment, however, is, in George's own words, *"like chicken eating eggs",* with waiting lists of over 26 weeks. George attributes the difficulty getting the medication he needs to NHS cuts- and specifically to a decreasing painkiller budget.

George's prescription needs to be re-ordered every month and reviewed every six months by a GP. In a surgery with high stuff turnovers and numerous locums *"every time I'm seen by a new GP I'm forced to have the same argument over and over again about the fact that I do, indeed, need the medication"*. A frequent, lengthy re-order and re-review process causes delays in obtaining the necessary medication; leaving George often in pain and feeling like he is *"fighting a losing battle"*. Similar discussions ensue whenever George sees a new physiotherapist- overall, he finds communication between medical professionals to be rather poor. *"The pain clinic used to be at the Mile End Hospital, I think things have gotten worse since, at least Mile End had a multidisciplinary clinic, where you could see a consultant, a physiotherapist, the pain service -all in one place. I don't think the pain team at the Royal London works like that now"*.

While he has not recently been an inpatient in the Royal London Hospital, George is aware of the challenges patients with chronic pain face when admitted to the hospital, namely around inability to continue taking the pain relief medicine they had been prescribed before admission: *"I did hear about patients' medication regime being altered when they go into hospital; that's a big problem for patients on the arthritis clinic. A lot of the nurses on the wards haven't seen Fentanyl patches at all and wouldn't know what they are"*. His concerns are echoed by other people we spoke to; an older female patient we met during one of our Enter and View visits to the older people's ward told us:

"I feel my pain could be managed better. They don't have tramadol?? In hospital and I can't bring it with me as they like to dish everything out. You lose control. I think it would be good to have an advocate sometimes. Someone who could talk to you about what you need to know from meetings with the the Dr or consultant and listen for you to the responses so maybe you can discuss with them afterward".

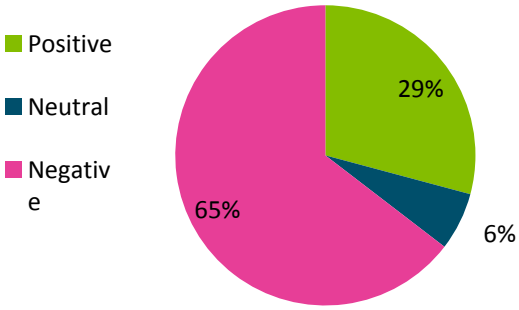
His case draws attention to a number of issues in regard to the care patients like her receive in hospital, primarily around:

- Communication between the hospital and GP surgeries.
- Excessive waiting lists for seeing a pain team specialist.
- A poor medication review system for people living with chronic conditions that are unlikely to change.

George also pointed out that a lot of patients dealing with long-term pain are prescribed morphine tablets and build a tolerance to it, to the extend that the drug is no longer effective in assuaging their pain. Nonetheless, once in hospital, they are often prescribed the same ineffective medication.

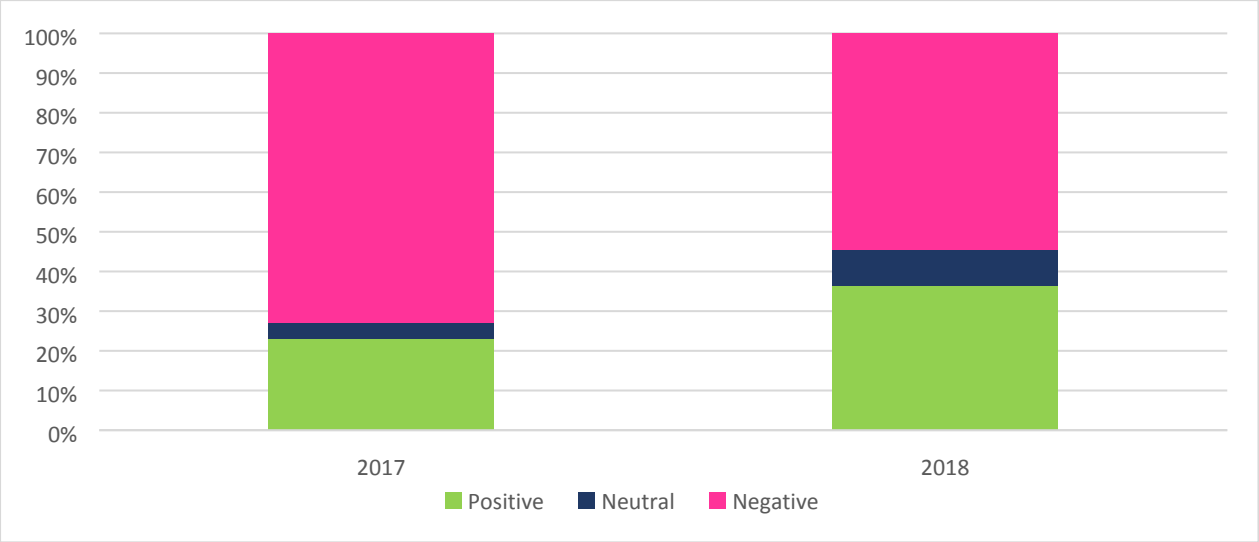
The wider picture

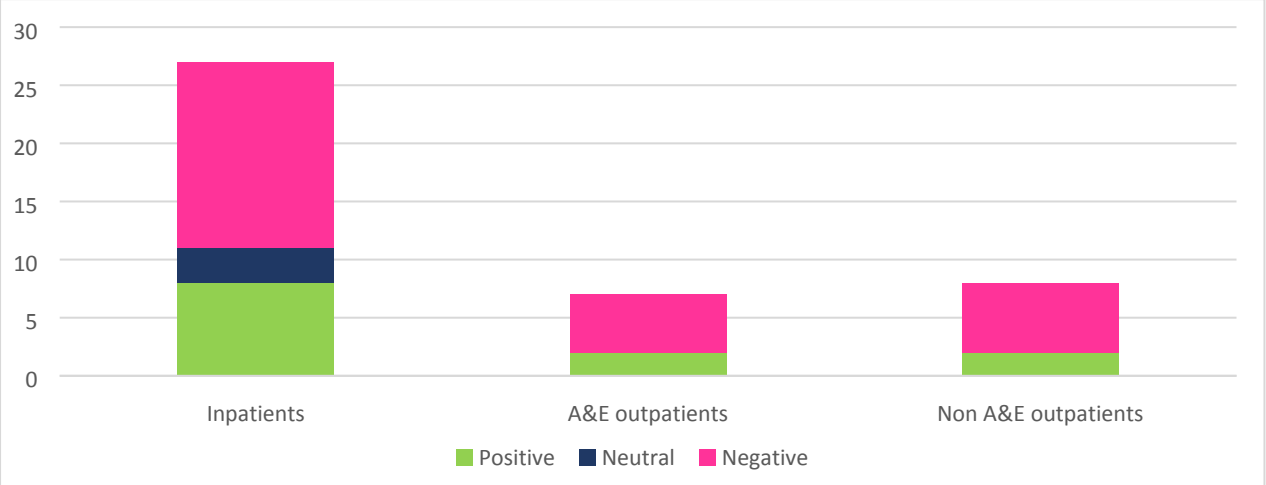
We have identified 48 individual comments from Royal London Hospital patients on the topic of pain management (26 received in 2017 and 22 in 2018).



Overall, patient experience of pain management was broadly negative.

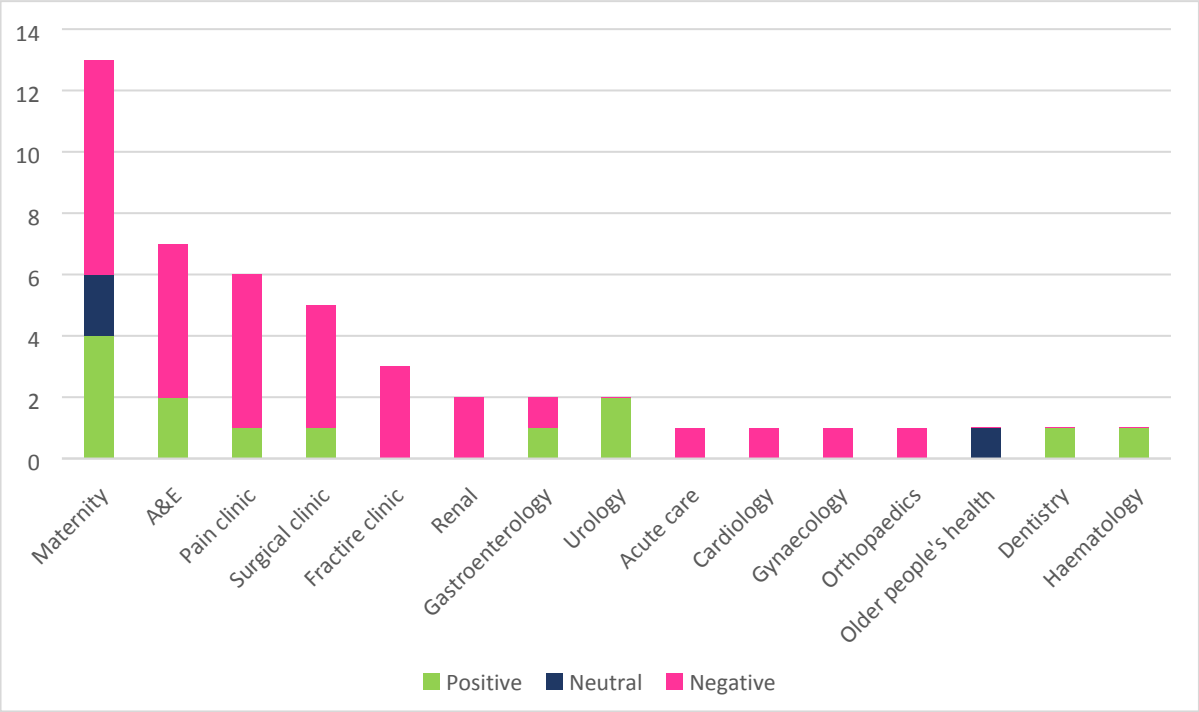
However, there seems to be a small improvement in patient opinion in 2018, compared to 2017:



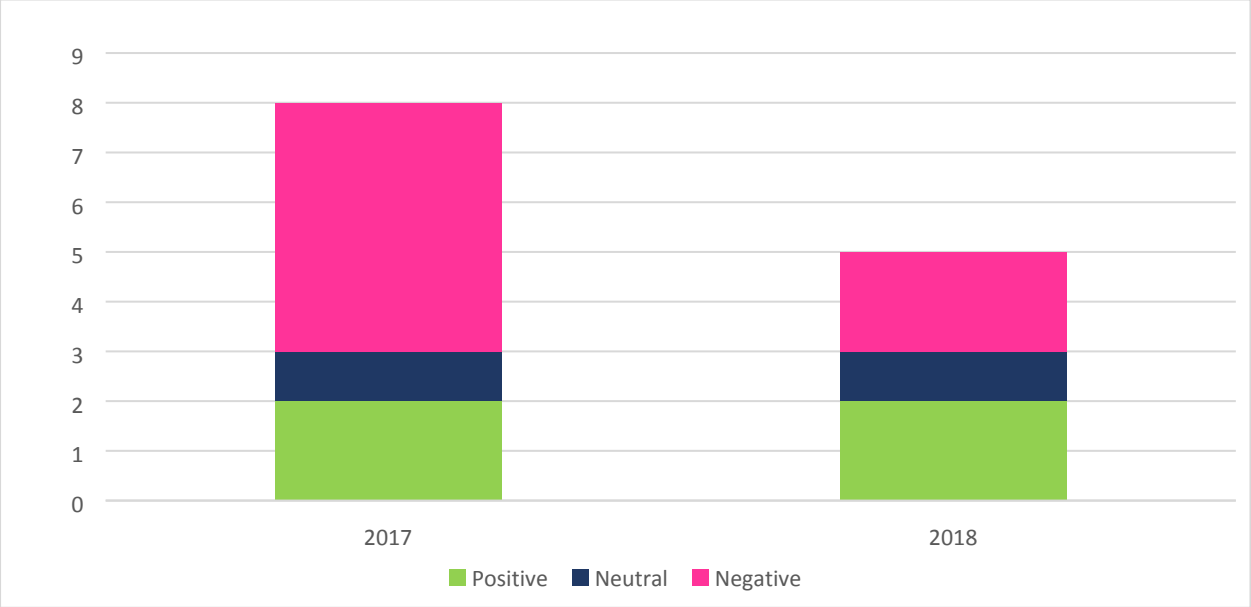


Hospital inpatients are the most likely to comment upon this aspect:

The Maternity and A&E departments receive the most feedback on pain management, but the pain clinic, surgical clinic and fracture clinic see a higher proportion of negative comments.



For the Maternity unit, the feedback received (showing less negative comments in 2018 than in 2017) is consistent with our monitoring of Maternity services, which shows a comparative improvement between 2017 and 2018



2017

"I had asked for epidural and it came very late, over 3 hours. When they finally came to administer the epidural, I don't know if the anaesthetist was a student, but he couldn't put the needle in properly he tried three times and failed. I felt him rupture my spine and when he wanted to try for the 4th time I refused although I was in pain and agony."

"The midwives at the labour ward and maternity ward are always so rude and snappy. They don't show any sympathy or compassion for labouring mums, and they are also very slow at administering pain relief. They just leave you screaming and writhing alone and in pain for hours. I had to literally beg like a screaming mad woman to be injected pethidine as midwives were reluctant to administer the drug because it would apparently make the baby drowsy, so they seemed to be happy to see me wail in pain instead. The entonox (gas and air) they gave me was deliberately made weak so did not have any effect on me; it did not even make me feel dizzy, but then neither did pethidine work as it was all deliberately administered on extremely pathetic low doses. When I called for an epidural they dismissed it saying no-one is available to supervise me on an epidural."

"I wasn't offered any kind of pain relief or told about it; maybe it's because I was going to have a water baby. But I walked in there at quarter past nine in the morning and I had the baby at ten to ten, so it was a bit rushed for everyone. When I gave birth to my second at Barkantine I used gas and air. This time, I felt quite in control of myself and don't feel like I would have needed it, but they should have offered it."

"I am taking a breastfeeding course and a pain relief in labour course. It is really helpful that RLH gives you opportunity to stay that informed and up to date."

2018

"The team of doctors and nurses helped me manage my Sickle Cell pain effectively and were very encouraging when it came to take the next step in my recovery treatment. I have nothing but the highest praise for the staff at the Royal London if it wasn't for them and their early intervention my husband and I would not be the parents of a healthy baby boy."

"My wife was given a pessary to help bring on labour and was checked at the time it was inserted. Despite us pointing out contractions had got a lot stronger later in the day (and that a monitor wasn't working well) she was never given a second physical check to see how dilated she was and it seemed like the midwives didn't really take her seriously when we said we thought she was farther along labour wise - we'd advise listening more closely to the patient in future even if they aren't making a fuss! When her waters did break it then transpired she was having a partial placental abruption, was 9.5cm dilated with no pain relief and the emergency button was pressed! After the button had been pressed the care was immediate and fantastic."

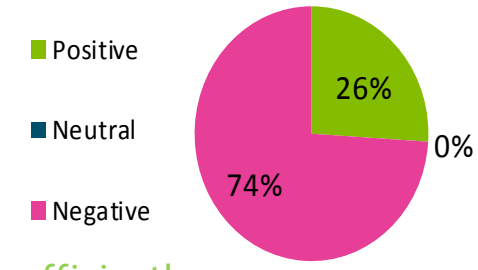
"I was recommended to have an induction and agreed to this only on the basis that there was an anaesthetist around and that the hospital was fully staffed - this was a Friday night. This is because last time I was not able to have an epidural because of shortage of anaesthetists. I was promised that there was and that at any time I wanted an epidural, I would be able to have one. I was induced, and it was incredibly painful. I was given two paracetamol and laughed at because it was early on. I kept asking for gas and air and was told definitely not as I could not have this for 10 hours. This was all said to me with an attitude of indifference and like I was a specimen or an animal. At some point, a doctor came in and I asked again for an epidural. I was told the doctor would come back. Eventually I was told that an anaesthetist was not available. Why were they just not honest from the start? I kept being fobbed off."

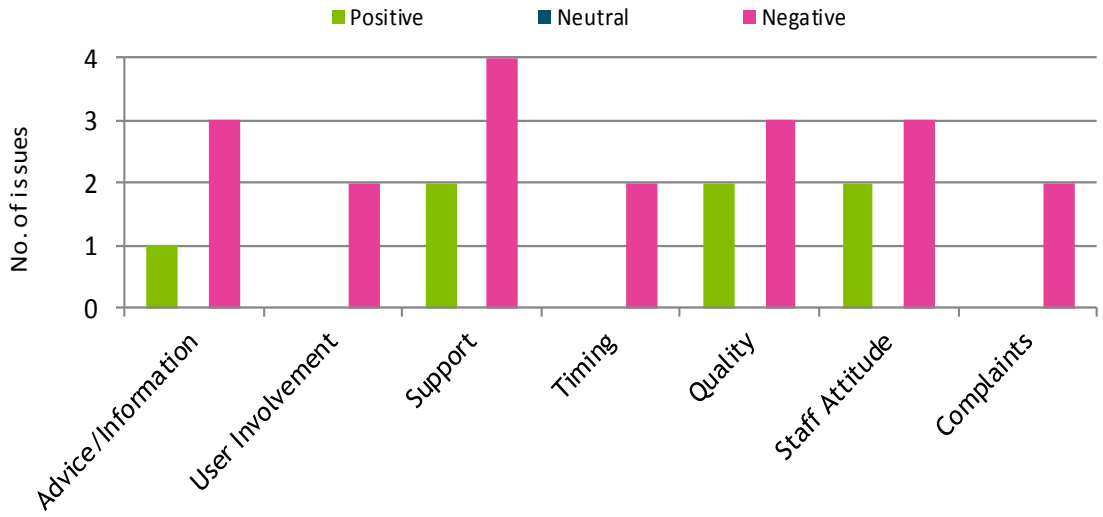
The pain management service

The Barts Health Pain Management Service is a multidisciplinary team comprising of doctors, nurses, psychologists, physiotherapists and acupuncturists specialising in helping patients to manage their pain.

Between January 2017 and August 2018, we have received nine comments about the pain management service and identified 34 issues.

Attitude about it is 74% negative. Patients feel poorly supported, poorly informed and insufficiently involved in their treatment.





In resemblance with Grace's story, one A&E patient also found that it is unclear what patients the Pain Clinic deals with and under what circumstances:

"I was first advised to "Go home and use same meds (that are not working) and rest" as if this wouldn't occur to someone with 20 years of Fibromyalgia. Took a debate with an A&E consultant to be admitted. Why? Because "The Pain Team do not see patients on A&E". Yes, seeing them and advising treatment with possible quick discharge might be too quick a system and more cost effective."

Several patients felt that their symptoms were being dismissed:

“Medical Consultant told me that my pain can’t be score at 8/10 because I'd be crying, not "playing games on the phone". Er... I'm an older technophobe and never play games at all. I was letting my carer (I'm disabled) know I’m been admitted. And trying to distract me from the pain by talking to a supportive friend by messages. I know pain! I practiced meditation for past 43 years! And can project a calm face. I was crying for over 30mins just before he came. But my culture believes in being strong and not engaging in any drama.”

“Visited pain clinic due to back pain as I had an operation before. The lady wanted me to walk further but I couldn't move that much. This job needs to be decreasing my pain, not increasing it.”

Patients also report poor communication and support from staff members; as well as por communication between staff members.

“Patient not happy with the poor communication with a staff member who was rude and belittling”.

“It doesn’t work at all- what they're looking for is just curing symptoms, not the cause- they give you lots of painkillers and each doctor deals very specifically with their own specialty- there is no communication between consultants and no framework for a more holistic view”.

“Complaint received from site - patient not happy that she has not received any aftercare after her procedure and with the information written in a letter to her GP”

Pain management in other departments

Patients' experience with support for managing their pain has been broadly inconsistent. Several patients felt properly supported, but the majority did not.

Multiple patients feel that their symptoms are dismissed by medical professionals; in some cases, they receive only over the counter painkillers, without any further investigation or explanation about their condition, despite being in severe pain:

"Patient reported that she came in to have a procedure two years ago and her nerves were damaged. it took the neurology team to confirm this. She would like to know how this could have happened and why no one would listen to her when she said she was in pain during the procedure." (Surgical Clinic, June 2017)

"I felt like I was treated like a nuisance and a fraud, yet I was in agonising pain and very frightened. If any of the medical staff had of bothered to ask me what the level of pain was, it would have been a 10. Instead they just gave me codeine, a walking stick and sent me on my way without even bothering to find out why a 23-year-old was in so much that I was unable to walk. (A&E, March 2017)

"Patient attended his appointment only to be told there was nothing they could offer him and that he should go back to his GP and get referred to the pain clinic" (Orthopaedics, March 2017).

"Mother is not happy with the recent clinic consultation her son had with the gastro clinician. She believes his manner was rude and of dis-interest. She also claims he appeared to have no knowledge of the patient's condition and failed to take her concerns regarding the pain her child suffers - dismissive." (Gastroenterology, March 2017)

There are reports of patients receiving what they feel is insufficient or inadequate pain relief:

"Patient got admitted after having a motor bike accident. Ended up with a fracture arm and knee. The patient feels a lot needed to be done to improve services, he felt his medication was not strong enough to help the pain, he was going through." (Fracture clinic, November 2017).

"I had to literally beg like a screaming mad woman to be injected pethidine as midwives were reluctant to administer the drug because it would apparently make the baby drowsy so they seemed to be happy to see me wail in pain instead. The entonox (gas and air) they gave me was deliberately made weak so did not have any affect on me; it did not even make me feel dizzy, but then neither did pethidine work as it was all deliberately administered on extremely pathetic low doses. When I called for an epidural they dismissed it saying no-one is available to supervise me on an epidural." (Maternity, February 2017).

Multiple patients report being told that they would receive painkillers and then never receiving them; this could be happening because of admin errors or staff shortages:

“The staff were rude and just ignored the fact that i was in pain. When i asked for painkillers they just did not seem to care and said they'll be back, which they never did come back with the painkillers.” (A&E, May 2018)

“I was recommended to have an induction and agreed to this only on the basis that there was an anaesthetist around and that the hospital was fully staffed - this was a Friday night. This is because last time I was not able to have an epidural because of shortage of anaesthetists. I was promised that there was and that at any time I wanted an epidural, I would be able to have one. I was induced, and it was incredibly painful. I was given two paracetamol and laughed at because it was early on. I kept asking for gas and air and was told definitely not as I could not have this for 10 hours. This was all said to me with an attitude of indifference and like I was a specimen or an animal. At some point, a doctor came in and I asked again for an epidural. I was told the doctor would come back. Eventually I was told that an anaesthetist was not available. Why were they just not honest from the start? I kept being fobbed off.” (Maternity- May 2018)

“Complaint about level of care received after undergoing surgery for cervical cancer. Patient had been advised that she would be given morphine to manage pain, however, this was not done, and both the doctor and the nurses could not confirm why the morphine had not been given to patient.” (Gynaecology, April 2018)

“I asked for some assistance to get some pain killers it's now 00.59 in the morning and no one here yet- I asked 3 hours prior to that.” (Maternity- August 2017)

“During her labour the family claim the midwife assigned to look after them was very rude and unprofessional in her approach to the patient. She left the room when the patient requested pain relief and showed no signs of being busy when the husband went to look for her to see why she was taking so long.” (Maternity, July 2017).

“My Wife went to A&E, they did the initial assessment and put her in the wrong place while her name was called out somewhere else. She had severe chest pain and was not given any pain killers. All this while she is pregnant. Absolutely atrocious, never been this bad, staff kept saying they will see you and never happened until 1 am.” (A&E, February 2017)

Several patients also report being discharged before they are ready to go home:

“Mr X has been admitted to the hospital 6 days and actually not recovered yet but has been forced to be discharged because the hospital needed the bed. HE said he was also waiting for 3 1/2 hours for painkiller medication. He said of this moment he is feeling a lot of pain and is not satisfied with the treatment he is receiving for the Royal London Hospital.” (Fracture clinic, November 2017).

“Patient admitted with 'T-bone fracture after a fall, claims to have been initially given inadequate pain relief. When she eventually found 'slight' relief, she states a doctor visited her and told her 'they needed to get her out of the hospital as soon as possible'.” (Fracture clinic, July 2017)

On the other hand, other patients report being seen and offered pain relief promptly:

“After surgery, I was waking up in recovery where, strangely, I had pain in my shoulder, which they didn't dismiss and provided pain-relief for. After some time in recovery, I returned to the ward where I was observed, given something to eat and drink, before being discharged home with information leaflets and pain killers.” (Urology, July 2018)

“I have now had my gall bladder removed on 12th February by the Hepa-bilary and Pancreatic team. The surgeon and team and the anaesthetist. I cannot tell you how grateful I am to him and his team and the clinical nurse specialist who helped to make my stay a lot more comfortable. My pain was kept under control after the operation. The nurses were very busy all the time running around doing so much and working so hard. Yes at times I didn't always get things as quickly as I would have liked but that was understandable.” (Gastroenterology, May 2018)

“I was referred to rheumatology for investigation into my chronic pain, I was advised at each appointment what tests would be done, who they would be carried out by and how long it would take to receive the results at each appointment, I saw numerous members of staff over the 6-9months that I was back and forth and they were all extremely helpful and accommodating, understanding and compassionate, I am a 32 year old woman with a debilitating illness which is invisible to others and I felt really comfortable to speak about my struggles in my day to day life, I got an official diagnosis and all paperwork and recommendations were sent to my GP in a timely manner and dealt with accordingly, I couldn’t be more thankful to the doctor and all of the staff From admin/reception - x ray staff and rheumatologist.” (Rheumatology, May 2018)

“What was good about my care was that I was monitored frequently by the health care assistance, and when asked for pain relief was given promptly. Also was given consideration regarding having my hot water bottle for the pain was greatly appreciated and helped my pain immensely”. (Haematology, April 2018)

“Kind, caring, pain relief within 20 mins of being there; I have to have open surgery on Monday to get rid of my gallbladder- if the care on the wards are like that then great!” (A&E, February 2018)

“On the Vascular Ward, I was moved into a side room and visited on a regular basis from consultants to nurses who ensured my stay would be comfortable and that my needs would be met. Everyone was of the highest professional grade and nothing to little for them to solve. Smiles a plenty, skills displayed and friendliness gave me a comfortable feeling. Even bringing me cups of tea, doing obs and gently giving me medications and injections which I hardly felt. All in all, my experience was a very positive one and I can’t thank those who pulled out all the stops to ensure a quick and pain free recovery.” (Surgical Clinic, November 2017).

“On call urologist came within 5 mins and diagnosed me and explained treatment options (lovely caring doctor) and arranged for my admittance on 9E. Was moved up there fairly soon and throughout the night pain relief was given regularly by a lovely caring nurse.” (Urology, September 2017)

“Triage nurse was caring and thorough. Taken straight to the emergency assessment cubicle. Seen by a consultant immediately who ordered pain relief which the nurse gave immediately.” (A&E, September 2017).

“I had an amazing birth experience! The head of midwives was present during my son’s birth found her to be very supportive and the service exceeded my expectation. They made me feel comfortable. I phoned to say I was coming and requested pain relief they administered this within an hour.” (Maternity, January 2017)

Conclusions and further research questions

This case study is only based on a small amount of available data; however, in highlights the need for further investigation in the following areas:

- **Communication between the pain team and medical professionals from other departments.**
- **Communication between doctors and patients on the subject of managing pain (including around safe dosages of various painkillers).**
- **Delays in receiving pain relief for hospital inpatients.**
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A wider research project touching upon these topics would be needed in order to assess accurately the scope of the issue and produce recommendations for tackling it.

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