

healthwatch

Tower Hamlets

DRAFT

Patient Feedback on Barts Health
Sept 2012-October 2013



Patient Feedback on Barts Health Sept 2012-October 2013

Contents

- | | | |
|----|------------------|--------------|
| 1. | | Summary of |
| | patient feedback | page 2 |
| 2. | | What is good |
| | | page 2 |
| 3. | | Top 10 main |
| | concerns | page 3 |
| 4. | | Next Steps |
| | | page 11 |

Appendices

Enter and View Visit Reports

- | | | |
|----|---|------------------|
| a. | Hospital - Renal Unit | Royal London |
| | | page 11 |
| b. | Hospital - Fracture Clinic | Royal London |
| | | page 23 |
| c. | Hospital - Oncology
(Rahere - 5B Ward) | St Bartholomew's |
| | | page 32 |
| d. | Hospital - Sexual Health
(Ambrose King Centre) | Royal London |
| | | page 40 |

Summary of Patient Feedback

1. Background

- 1.1 This report is based on the analyses of patient feedback from:
- four Enter and View visits undertaken by Healthwatch members over October and September 2013 to:
 1. **Ambrose King Centre** (Sexual Health) Royal London Hospital
 2. **Renal Unit** Royal London Hospital: Outpatients, Haemodialysis Unit and Inpatient - Renal Transplant Ward (9F)
 3. **Fracture Clinic** (Outpatients) Royal London Hospital
 4. **Rahere Ward** (Cancer) St Barts Hospital
 - 900 comments collected between September 2012 and October 2013 from local patients at community events, online on the Healthwatch website and Rate Our Service, workshops and phone feedback and interviews.

2. What is good?

- 2.1 Generally patient comments present a very positive view of the clinical care provided at the Royal London Hospital.

“I think doctors do their jobs well I always understand what they say and I feel as if they really care for me in a special way. They are friendly and loyal, and I feel I get excellent service therefore I’m very happy with the doctors.”

“I have to mention how very impressed I was with the professionalism and knowledge of the doctors and nurses at the new Royal London hospital. .. Overall it was a top service I received from them and I was very pleased.”

- 2.2 Things that were mentioned when describing a good service were:
- seeing the same consultant
 - seeing the senior consultant that you asked for at least once
 - having the right test results when you see the consultant
 - having enough information and time to ask questions
 - being seen on time, given further advice and being kept updated
 - people being friendly, smiling, taking the time to say hello or welcome you
 - getting an appointment straight away
 - giving advice in a non judgemental

“I have a regular consultant that I see. He is brilliant. He talks and he listens and he’s helped get my condition stable.”

- 2.3 Particular areas and actions that received a number of positive comments were:
- Children’s services both A&E and general.
 - A&E service - but not the waiting times. People feel that they are given a more thorough examination at the hospital by more specialist doctors.
 - The stroke team and cardiology teams although patients also mentioned problems on discharge and appointments.
 - Text reminders about appointments and being able to book appointments online.
 - Hospital cleanliness and the quality of rooms

“My neighbour had gynaecological surgery at the Royal London six or seven weeks ago and was at her third Pilate’s class! Nurses were pushed but were very good. They put her in a single room across from the nurses’ station as she was probably the oldest patient on the ward. She felt the care was very good and liked having a single room.”

3. Top 10 main concerns from Tower Hamlets re Barts Health services

The most common concerns raised by patients were:

1. **Administration and referral processes**
2. **Shortage of nursing staff**
3. **Maternity - aftercare and discharge**
4. **Waiting times in A&E**
5. **Food**
6. **Environment**
7. **Slow and poor discharge processes**
8. **Hospital Transport**
9. **Incontinence service**
10. **Complaints processes**

4. Administration and referral processes

- 4.1 The problem raised by the largest number of patients was not the quality of clinical care but the administrative systems around appointments. This included poor referral processes from the GP, long waiting lists/times to get an appointment, poor administrative processes (letters late, wrong appointment times, wrong phone numbers, wrong patient, wrong location) and appointments frequently being postponed.

“You receive a letter that tells you to phone a number within five days to make an appointment. You can’t get through on the phone or you get through and they say you’re in queue. Then it’s “you are number five in the queue, you are number four in the queue . . .” Somebody finally answers and asks you what department you want and then says that this is the wrong department. My GP phoned the consultants clinic and they said that the clinic was full for weeks. He phoned again an hour later and was told the list was open again. . . .My doctor referred me to the foot clinic they saw me once and told me they will call me for another appointment however it has been over three months and I haven’t heard since. But

I did find the foot clinic to have a very good service. Doctor was very helpful and he knew what he was talking about and I was satisfied with care.”

- 4.2 From a patient’s perspective the current systems couldn’t be further away from being patient centred. People feel that they are not being given fair access to appointments and that the system is the problem. Many feel that it is incumbent on them to try and navigate through a complicated system, often needing to complain to get results. This can have a very detrimental impact on their health and their recovery.

“I’ve not been here for a while as I have spent the last two years trying to get an appointment for someone to resolve my lower back problems - the only reason why I was seen today was because I went through the Complaints’ Department. I had my surgery in August 2011 and was seen six weeks later by the Physiotherapy Department (Royal London Hospital) and was told that I will receive an appointment at the Pain Clinic at Mile End Hospital. I waited for a couple of weeks, but never received an appointment. I tried to chase-up my appointment, just to be told that I missed it (this bearing in mind I never received the appointment letter in the first place). So far it’s been a bit of a nightmare to get an appointment...”

- 4.3 This frustration is compounded further by having to wait long periods when you actually do make it to the relevant clinic for your appointment.

“Few months ago I went for my outpatient appointment in cardiology department at RLH for 3 o’clock appointment but was seen at 5pm. No one came out to say why the appointment was running late. Due to my lack of confidence I did not show my frustration.”

- 4.4 Then often the consultant doesn’t have the right test results when you are finally seen or they explain it’s an exploratory appointment and you’ll have to come back and see another person and the whole appointments process nightmare starts over again. People are waiting years for something that could be sorted in a couple of months if the administration systems worked effectively. This often compounds illness and injury and leads to more expensive treatment further down the line. It is surely also a massive waste of resources as tests are often repeated unnecessarily as appointments are arranged at the wrong times.

- 4.5 One suggestion from a patient was that certain treatments may not need to be undertaken in hospital and should be made available more in the community.

“I had an appointment at Therapies Outpatients Department, Barts Musculoskeletal Therapies. It had taken four months to get the appointment and it was then for in a month’s time. I had had a hip replacement eight months ago. The letter said that the appointment was at 9.15. When I got there (which it is difficult to get anywhere that time of the morning) the receptionist told me that the computer said my appointment was at 9.45. I showed her the letter with 9.15 on it but she didn’t seem to care. The doctor or physio said I had to come and do exercises for six weeks. I said why don’t you just show me the exercises I have to do and I’ll do them at home. I don’t want to have to travel in every week when I could just as easily do them at home. He said that was fine and did some stick figure drawings of exercises that I could do at home. Why don’t they do that for more people? It would free up the waiting lists and people would get seen when they need to and not 5 or 6 months later. Why couldn’t they just go to their local gym and do it.”

Questions

- a) What is the current system for allocating appointments? We would like to know how the overall appointment process works once appointments are requested from GPs, Consultants, and clinical departments within the hospital.
- b) What is the response timeframe for answering telephone calls, responding to letters, sending out appointment letters?
- c) Who decides on the appointment allocation of patients per clinic?
- d) Who decides how many consultants are allocated to each clinic?
- e) What are the options for patients if consultants miss appointments?
- f) Why do consultants run late for appointments?
- g) Why are planned appointments cancelled to cover for emergency appointments?
- h) What are the plans to improve the current administrative and appointments process? Will this be addressed through the move to Electronic Patient Records and implementation of a single patient system across all sites (PreView)?
- i) Is there likely to be more rather than less issues with new staff restructuring and loss of administrative staff?
- j) Are there any CQUIN's demands for the appointment system?

5. Perceived shortage of nursing staff

- 5.1 We received far fewer comments this year regarding the poor attitude of nursing staff compared to previous years. Comments tend to now focus on a perceived shortage of nursing staff on the wards.
- 5.2 The perception from many patients is that there is inadequate staff in a lot of areas and that there is a problem with bank staff and supply nurses.

"I feel that 7F is short of staff and they always take on additional agency staff; I am not happy with the agency staff as it seems like they don't know what they are doing (i.e. don't know how to put on a medicine pack on my son)...agency staff should be trained properly before they're sent to specialised wards...when I see agency staff I don't ask for their help as I don't feel reassured that they can do their job properly."

"The day after my operation I was high on morphine, firstly I didn't know where the alarm was and when I did find it I couldn't get to it. I couldn't see the nurse and nobody came in. In the end I called my family on my mobile phone to get a nurse to come and see me. The staff are very helpful though"

"..due to staff shortages sometimes I have not been given my dinner as I have been unable to walk to get my dinner from the ward corridor."

- 5.3 We understand the new ward layouts can leave patients with the perception that there are fewer nurses even if nursing levels have remained the same. However it is true that nurses are not able to keep an eye on as many patients as they were in the old wards and they are less visible to patients. This has the potential to leave patients feeling isolated which leads to them feeling unsafe and increases anxiety. You lose the sense that nurses are always around and patients feel insecure.
- 5.4 This also leads to the nurses being overworked which leads to them appearing or being rude and abrupt to patients who would just like a bit of reassurance. It also leads to a deterioration of staff moral and there is a sense that in some wards good staff are leaving.

"You can't complain about a nurse who is looking after about seven patients all on her own. You just have to give them credit for their hard work and effort."

- 5.5 We also picked up comments about patients feeling that the wards were short staffed at night and at weekends.
- 5.6 The financial review is suggesting nurse to patient ratios at one nurse to seven patients. It is clear that patients in the majority of cases do not feel that this will provide them with the compassionate as opposed to clinical care they would desire. We also feel that this will impact on patient safety.

Questions

- a) Is there any recognition that the new ward layouts require a higher nursing ration than the national standard to meet patient safety?
- b) What is the percentage of bank and supply nurses at the moment?
- c) What is the percentage of bank and supply nurses over the weekend?

6. Maternity Services

- 6.1 Generally mothers are very positive about the surroundings of the new maternity wards and feel that the Royal London maternity services have improved. We received very few negative comments about the care during labour.

"I gave birth at the old Royal London hospital and the service was really good. The support from the midwife at the hospital was wonderful and I also got support when I went home as they came to visit me at home."

- 6.2 The most common negative theme from mothers related again to a sense that there were insufficient staff particularly in relation to aftercare.

"I felt that the nurses were working very hard to keep every patient happy. It's not an easy job so I have to give them credit"

"The staff seem very busy there and if you call them for their assistance they would say 'give me two minutes' and it will take two hours for them to return."

- 6.3 Staff shortages may also go some way to explaining some of the issues relating to poor discharge that we picked up.

"I waited four days to be discharged from the hospital and there was nothing wrong with me."

"I was discharged by a student nurse . . . and she also gave me all my files that the hospital should've kept. I even had to call a community nurse as no midwife or nurse checked me before or after my birth."

"The new Royal London hospital lost my files which meant according to their system my baby wasn't born and I was forced to stay in the hospital for an extra night. My files were later found in the triage ward and I couldn't wait to leave the hospital as I wasn't getting the support I needed there."

"After I had my baby I was asked to leave the room, discharged home very quickly as they needed the room for another patient. I had to sit in the triage corridor with my suitcase, baby on my lap, on a plastic chair surrounded by moaning women until my husband came to pick us up."

- 6.4 We are still picking up issues about a different quality of midwifery care being provided to non-English speakers.

“When I gave birth at the Royal London hospital the staff thought I couldn’t speak English and were very rude to me. But when I spoke up for myself the staff realised that I could speak English and their behaviour towards me changed. The staff became a lot friendlier and treated me well. I know they treat patients who cannot speak English badly and this is really bad and unfair treatment”

Questions

- a) Are the ratios of midwives to mothers and babies at national standards in the aftercare wards?
- b) Is there a current shortage of midwives? Are they able to fill all vacancies?

7. Waiting times in A&E

- 7.1 Patients are very positive about A&E services at the Royal London. *“It’s quicker to go to A&E and you seem to get a proper assessment and tests there and then.”* There is difficulty getting appointments at some GPs and people feel the quality of assessment is not always good. *“You are assessed better at A&E”.*
- 7.2 However waiting times are a major issue especially for people who are in pain. *“I had to wait about 3-4 hours and I was in a lot of pain therefore, wanted to be seen as soon as possible but I had to wait.”* One patient mentioned being delayed for six hours at the hospital A&E for a sickle cell attack resulting in premature labour of her son.
- 7.3 People with long-term conditions felt they should have more consideration for people who may be frequent visitors *“... more sympathetic staff at A+E to hear patient’s needs who have multiple illnesses and need more care”*. And that there should be some mechanism to fast track frequent visitors *“every time my son is not well he has to be readmitted as a inpatient to 7F, however in order to readmit him we have to always go through A&E, we can’t come direct to the ward. And every time we go to A&E they ask the same questions again and do all the tests again; this is very frustrating for us, on one occasion there was a two day gap between discharge and readmission and we had to go through the whole A&E process...why can’t they just let us go to the ward?..This process usually is very stressful to my son.”*

Questions

- a) Do they assess people as to the level of pain they are under on arrival?
- b) Why can’t people who are frequent visitors be fast tracked through A&E?

8. Food

- 8.1 There are mixed views about the food provided. Some patients commented that they do not like the food due to blandness of taste and lack of variety on the menu and other patients feel patients should not expect too much from a hospital, therefore the standard is ok and at least you are given a choice.
- 8.2 In some areas it was not so much about the quality of food but about:
- not enough food,
 - food being cold when it arrived,
 - food running out before it reaches patients, and
 - patients not being given enough time to eat or not being given enough help to eat with food being taken away without being touched.
- 8.3 Not all patients have family to bring in extra food and there is a sense that this is necessary.

“After my operation I was on a ward for seven days, on three of the days I didn’t get the food that I ordered, on one day I got no food at all apart from sandwiches, and I certainly don’t want cold food when I’m in hospital. Out of the seven days I was on ward, only on three of those days I got the food I ordered, and even then it really wasn’t very nice.”

“The food is awful, not appetising and bland. The halal food is always curry. Not all Muslims are south Asian and I don’t like the curry.”

9 Discharge

- 9.1 Patients being discharged when they or their family felt it was too early or before appropriate care packages were in place

“It seems hospitals want to discharge patients quickly...they discharged my father and he was not well enough to be discharged...although we highlighted that he was not feeling better, they insisted on discharging him... so we took my father home, but he could not cope due to the pain, we took him to the doctors and the doctor said that he should return to the hospital - this whole situation could have been avoided if the hospital doctors decided that he was not ready for discharge- it seems once they make their minds up, the decision has to stick!!”

- 9.2 Patients self discharging because of the noise, temperature on the ward and lack of air.

- 9.3 We have heard of several patients self discharging. One was in the cardiovascular ward, they left because it was very noisy with all the monitoring equipment and they couldn't get any sleep. Other people have left because of the temperature on the wards being too hot and stuffy and they felt as if they couldn't get any air. This seems to be a fairly significant safe guarding issue as there is obviously a reason that they are in hospital in the first place and to get up and leave could, one would think, have potentially life threatening consequences. We have raised this issue with the Chief Nurse and understand that an audit of the number of patients self discharging is currently taking place and we will receive a copy of the audit.

- 9.4 Patients having to wait a long time to be discharged on the day they were leaving and being left to wait in the discharge lounge while prescriptions were being filled.

“My mother was discharged in the morning but had to sit around and wait all day until 12 at night for her prescription to be filled.”

10. Incontinence service

- 10.1 Over the past 12 months we have picked up issues with the adult incontinence service.

“My mother had a very bad experience with district nurses and the Incontinence service once discharged from hospital- my mother was without incontinence pads (& correct size pads) for almost two months due to problems of communication between the District Nurse and the Incontinence service . . . the nurse was blaming the incontinence service for this mistake and the incontinence service blamed the nurse for this mistake. Currently we are still waiting for the incontinence pads for the last two months we have been borrowing from other people.”

“Getting through to the incontinence service is very difficult as no one answers the phone, it seems only 10% of calls are answered and if you leave a voicemail it takes them two days to get back to you- based on my experience I would say the incontinence service is not that good for the reasons that is difficult to access the service and once you get through no one can be held accountable for their actions/ lack of actions; it's very frustrating!!”

Question

- a) Who has overall accountability for the incontinence service?

- b) Could we have an outline and information on the incontinence service in order for us to properly inform patients?

11. Hospital Transport

- 11.1 We continue to receive many comments about the reliability and lateness of the patient transport service. *“Hospital patient transport is not reliable, sometimes they come early, sometimes they come late, but they never arrive on time...”*

“I often have to wait about 55 minutes for the driver to come and pick me up after leaving the ward. However I do think the drivers are very helpful, and always help me get in and out of the car. Getting to the hospital is not as bad, as the drivers often turn up on time but the problem occurs when leaving the hospital.”

“Patient transport is generally good; I use this service regularly and I am grateful I am offered the service... however they are always late by an hour from the appointment time given to you, but I can understand why they are always late they have to pick up so many people along the way...the delay by patient transport also delays your appointment time at the hospital, as you get seen later than the time given to you...it would also be useful if patient transport can pick you up straight away after a hospital appointment- you normally have to wait an hour...and whilst you are waiting no one attends to you- it would be nice to get a cup of tea!”

Questions

- Have there been any user surveys undertaken regarding patient transport services recently?
- We understand that the service has changed or is about to change. Could we have an update?
- Isn't it possible now to use technology to provide a tracking system as to where your vehicle is so people could get on with doing other things while they waited?

12. Environment issues

- 12.1 Most people are very complimentary about the new hospital mentioning it is clean, modern and spacious. But there are a number of issues frequently raised:
- **Layout** is complicated, there needs to be better signs to direct patients.
 - **Lifts** - People find them hard to use and confusing
 - **Temperature**- some wards are hot (High dependency Unit) and some are freezing from a patient perspective (Renal Outpatients)
 - **Lack of air** - not being able to open the windows makes it very stuffy and sometimes stifling
 - **Noise**-monitoring equipment makes a lot of noise at night making it difficult to sleep.

13. Complaints and PALS procedures

- 13.1 Patients have complained to Healthwatch Tower Hamlets about:
- difficulty finding out the complaints procedure and who to contact to make a complaint
 - the timeframe for responding to complaints?
 - procedure being too complicated, hard to navigate through and too long

Questions

1. Could we have an update on the complaints procedure please, including the expected response time?
2. Is there a proposal for Healthwatch to receive a regular complaints analyses report?

13.2 PALS

13.3 Recently we received concerns that patients are finding it difficult to access the PALS service i.e. patients are telling us that they find it difficult to get through to PALS service on the phone and when they do manage to get hold of them they are requested to make an appointment to see them, which can take a long time. Patients that have used PALS service in the past have said that they prefer the drop in option as it was accessible when they felt distressed and needed to see someone quickly for support or advice.

13.4 Also PALS signposting does not appear to be very good, for example patients are still turning up to Trust Offices (Mile End Hospital) to see a PALS officer and in some cases they have been advised to turn up to Trust Offices on the advice of hospital staff both at Royal London and Mile End Hospital.

13.5 We were notified in July 2013 that Barts set up a call hub that will deal with all PALS calls. In addition the drop-in service for the public at The Royal London, Whipps Cross and Newham was being replaced by a booked appointment system for patients. Apparently this system would be piloted for three months.

Question

1. What has been the outcome of the PALS service pilot?

14. Next Steps

Healthwatch Tower Hamlets has a statutory right to a response to requests for information within 20 working days. Section 224 of The Local Government and Public Involvement in Health Act 2007.

On receiving the responses for further information from the relevant departments or wards of within Barts Healthwatch Tower Hamlets Advisory Group will develop a number of recommendations to Barts NHS Trust.

Appendix 1

Enter and View Visit Royal London Hospital Renal Unit

Barts Trust

9th Floor, Royal London Hospital, Whitechapel E1 1BB

Date: Monday 28 September 2013 10.00-12.30 & Wednesday 9th October 10.30-12.30 (Two visits)

Healthwatch Tower Hamlets E&V Representatives: David Burbidge; William Colverson; Julia Avery; Dorbesh Ali

Healthwatch Tower Hamlets Staff: Shamsur Choudhury

Barts Contact: Brenda McManus (Renal Consultant Nurse)

Purpose of Visit:

1. To ascertain feedback from renal outpatients, renal inpatients and the Haemodialysis Unit patients on their experience of services at the Renal Unit.
2. To find out from patients their suggestions for improving the service at the Renal Unit.

The visit to the Renal Unit was undertaken over two days, on the first visit Healthwatch representatives spoke to hospital management and spoke to patients in the 'Renal Outpatient' waiting areas (Reception Area A&B). Due to time constraints it was not possible to visit the other services provided by the Renal Unit and it was decided to undertake a follow up visit to speak to renal inpatients and haemodialysis patients.

General information about the Renal Unit

- Barts Renal Unit is the second biggest renal service in the country and provides care for patients in North East London; parts of Essex and surrounding areas. The majority of the renal service is provided from the 9th floor of the Royal London Hospital.
- The Renal Unit offers treatment to patients at all stages of the kidney disease pathway. This ranges from diagnosis of early kidney disease through to caring for patients with all forms of advanced kidney disease, including dialysis, transplantation and end of life care.
- The Renal Unit has 50 inpatient beds; 88 Haemodialysis machines.
- The majority of patients access the service via A&E.
- The Renal Unit had a 22.5% response rate of patients completing the 'Friends and Family Test'- this is a good response rate compared to other Barts Health Departments/CAG's.
- GP's have voted the Renal Unit 'Team of the Year' for information sharing.
- The Renal Unit has a patient group and currently three patients are members.
- Patients can view their results online via 'Renal Patient View' - www.renalpatientview.org
- Current challenges: (1) The haemodialysis ward can feel cold for patients as they have to stay on the dialysis machine for four hours. (2) there is currently a lack of entertainment available for dialysis patients- there is no Wi-Fi available in the hospital so patients can't bring their laptops to pass time also as most of the patients are categorised as 'low income' the hospital entertainment system might be too expensive for them to access.

Patient Comments/Feedback

Renal Outpatients Comments (Reception Area: A & B) - Date of Visit: 28/08/13

Patient 1

I would like to see the same doctor; every time I see a different doctor, I also think they need to employ more doctors.

Male, 40's, Middle Eastern

Patient 2

I am generally happy with the service I get here; however I have this particular health problem and the consultants are not able to identify it and can't find a solution to help me. Also they keep changing consultants, would be nice to have some consistency...the blood test is also quite time consuming, you have to wait 30-40 minutes.

Male; 40's, Black Caribbean

Patient 3

It's a good service ; don't really have any suggestions for improving it; I am happy how the doctors/consultants explain things and the treatment and care is very good...blood test takes a long time, it can take up to 1.5 hours.

Male, 40's; Pakistani

Patient 4

I'm happy with the service I get here; I am happy with the appointments and also with appointment waiting times. The doctors and nurses are great as they are helpful and informative and they also give you time to ask questions. Reception staff are also good. The only negative is the ward is quite far from the main entrance of the hospital.

Male; 70, White British

Patient 5

I am generally happy with the service I get at the Renal Outpatients service; the doctors and nurses are very good; they review my treatment very well. The reception staff on the 9th floor are also very good (however the reception people on ground floor are not very helpful). Appointment waiting times are generally good, but on the last appointment I had to wait 45 minutes. The only thing I am not happy about is the blood test; it takes over an hour to get this done.

Female; mid 20's; Asian

Patient 6

The doctors here are good; they discuss and explain things properly and give patients time. Patient transport can be an issue I have been waiting here for over an hour to be picked up.

Female; 60; White British

Patient 7

I am generally happy with the service I get here, getting a blood test done can be quite time consuming... usually you have to wait at least 30 minutes before seen by a nurse.

Male; 38; Bangladeshi

Patient 8

I am happy with the staff here, they are friendly and caring...blood test can take 20-30 minutes and it can take at least 1 hour before being discharged, this is mainly due to waiting around for patient transport to pick me up.

Female; 76; White British

Summary of Patient Feedback (Common Themes)

- Majority of patients seem to be happy with the service they get from renal outpatients; patients have highlighted that they think staff (doctors and nurses) are very good as they explain things properly and give them time. Most patients also seem satisfied with the appointments process and also seem happy about waiting times when visiting renal outpatients.
- Majority of patients commented that they are not satisfied with the blood test waiting times.
- Some patients mentioned that consultants keep changing at every appointment; they feel there needs to be continuity of being able to see the same consultant on different visits.

Haemodialysis Unit Comments - Date of Visit: 09/10/2013

Haemodialysis patients visit the Renal Unit three times a week and have to be attached to the dialysis machine for four hours per day. The Haemodialysis Unit runs three sessions each day (7.30-11.30am, 1-5pm & 5.30-10pm); during the morning session, 28 patients use the dialysis machine; in the afternoon a further 28 patients use the dialysis machines and in the evening 12 patients use the machines- over the course of the day the haemodialysis unit serves 68 dialysis patients.

Patient 1

In general the service here is good, nurses look after me well...but it gets very cold here especially if you are laying down for over four hours- so they need to put the temperature up a bit. Could do with also improving Patient Transport; they always bring me to the Renal Ward 1.5 hours before my appointment time; it's quite frustrating waiting around for that amount of time.

Male; Late 60's; Caribbean

Patient 2

Staff here are very good; they look after me very well and try their best. Patient transport also takes me home; I am grateful for this service. It's very cold in the ward; they need to put the temperature up so its feels warmer for us.

Male; 70's; Bangladeshi

Patient 3

The service here is very good; I am very happy with the staff as they are very caring. I also like the patient transport service, I am happy that they take me home. I feel really cold here, and also very hungry, before they provided sandwiches, now they only provide tea and biscuits. It would be great if they could provide sandwiches and also made the ward a bit warmer; as you can see I have two blankets over me- it's freezing.

Female; 68; Cyprus

Patient 4

I feel hungry, two pieces of biscuit is not enough, I would like a sandwich...I am also feeling cold; both of these factors make the experience of coming here uncomfortable. They also stopped providing tissues near the bedside. The nurses and doctors are great they look after you well.

Female; 50's, African

Patient 5

It's cold here (I think the temperature is set like that for infection control), nurses could make more of an effort to explain test results (chemical imbalances on the test results). The curtains are loose and currently being tied up with plastic bag- that's not very professional. Nurses are generally very good and they look after you well. However doctors should interact with patients more, I hardly ever see any doctors on the wards. I noticed some patients complain of being hungry, I think they should provide sandwiches and the decision to provide sandwiches should be based on individual circumstances i.e. if they are old; living on their own, if they can afford it- there are a lot of patients here that are not able to feed themselves before arriving on wards or can't simply afford to buy a sandwich.

Male; 50's; Black Caribbean

Patient 6

I have been receiving dialysis treatment for about eight years now as I have kidney failure. Overall I would say the service here is excellent, the doctors and nurses are fantastic. There are times when they seem short staffed (i.e. lunch time) and when this happens this has an impact on the service as a whole because kidney patients who are on dialysis like myself regularly 'crash' which means professional care is needed constantly around the clock when people are here- I personally think if two people crashed at the same time they won't have the staffing capacity to attend to both patients - which is frightening really. There are about 28 beds on this ward, and everyone is receiving treatment at the same time therefore nurses are constantly busy, which means I have to wait a long time before I get the chance to talk to a nurse or physically see one.

One big problem I have here is that it is extremely cold. I mean even wearing two to three blankets doesn't keep me warm and most of the time I am sitting here freezing, I'm here hours on end it really affects me. At the old hospital it used to be warm and cosy but here it's very cold, they really need to put up the heating. However the new hospital is much cleaner compared to the old hospital and they also have modern equipment.

When an emergency rises I've seen staff act quickly and efficiently which is extremely important and good because when someone crashes time really isn't on your side. I think I've bonded with staff here I've been coming here for a long time I know most of the staff now; overall they're all very good. This ward is full of complex illnesses it's really tough here; doctors and nurses are excellent here I've got no worries about that.

Most of the time I arrange my transport home myself but I do have days where I'm not feeling too good and get a cab home. I have days when I'm really not feeling good after coming off the machine and the staff make sure I'm ok (carry out test) before letting me go home which is very reassuring- usually nurse could tell how I am feeling after coming off the machine. I think on some days when I am not feeling well the patient transport service could benefit me.

They use to provide sandwiches before at the old hospital but they've stopped that now, some people complain of being hungry, however they still provide tea and biscuit.

They use to provide a social worker that would visit the ward and support patients with their problems e.g. getting the right benefits, etc, yeah he helped me with my benefits...now I don't see him much, and I think they have reduced his hours, which is a shame.

Male, 52, White British

Patient 7

The service here is generally good and I'm happy. I do get those occasional visits from doctors and I think their care is very good; they are friendly and polite to me. It's extremely cold in here and multiple blankets does not really help, they really need to turn up the heating; It wasn't this bad at the last hospital (old RLH). I'm always shivering which I am not happy about.

I have been receiving dialysis treatment for around 12 years now and that's such a long time ... 'I'm really getting fed up'. I believe the doctors and nurses are doing everything they can but I feel as if my body doesn't want to put up with all these medications and treatments. Like many patients I come here for dialysis Mondays, Wednesdays and Fridays for four hours each of those days.

I've got these terrible aches and pains on my legs and back, the doctors don't really pay attention to this and just give me ointments which are not helpful, I've been to see my GP and this problem really isn't getting better.

Tea and biscuit are provided, however I don't really eat it and I am not bothered if they don't provide it.

Female, 60's, Bangladeshi

Patient 8

I've been receiving treatment for five years now and I'd say the care and service isn't that good here. Some nurses are rude and don't always attend when I need them...I am not happy about this. The doctors are excellent around here I'd say I get better service here than my own GP surgery. But sometimes they rush and I feel as if I don't get enough information on my care. I think doctors shouldn't rush they should give me enough time and adequate information about my care.

It is always cold in here they need to turn up the heating. No food and drinks are provided to me, which I think is not good. We sit here for hours sometimes even get hungry and I have no choice as I am stuck on a machine.

Male, 60's, White

Patient 9

I've been having treatment for two years now, the doctors here are very good and I feel that I always get top quality care from them; and the nurses are nice when they want to be. Sometimes the nurses are very busy attending to patients and some days when they are short staffed there is madness on this ward. I think they need to have more nurses on the ward, I never get the chance to speak (or ask for anything) to a nurse during the four hour session and I will only get to see them when I am leaving.

Male, 65, Bangladeshi

Patient 10

I have nothing but praises for the nursing staff and doctors -they are excellent. The new hospital is very clean and nicer than the old one. My only complaint is that I am freezing cold, I have already been given two blankets but there are no more left for me to have.

Female; 30-40; Mixed Background

Patient 11

I think the facilities in the new hospital are a lot better and it is good that there is much more space. I think the nursing staff are great, but I think that they are still understaffed. The shortages of nursing staff gets worrying at the end of the dialysis session, as most people come off the machines at the same time and this is the moment when most people begin to crash- so a select handful of nurses cannot keep an eye on everybody. I also think the ward is freezing.

Female; 40s; Black African

Patient 12

The nurses and doctors are "ok" however I think that the nurses don't keep an eye on the patients the whole time- some of the beds are not in eye view of the nursing station and sometimes the nurses aren't always at their station. I get very anxious when I am in one of those beds, as the nurses may not notice if something happens to me. I think that there should be at least one nurse to a bay- I feel the ward is short staffed. I preferred the old hospital because the doctors would come straight away when needed but in the new hospital they don't. Also it takes a long time to get on to the ward, in the new hospital, as it is on the 9th floor and the lift takes a long time. I also feel very cold (She was visibly shivering) and they won't give me another blanket as they don't have any left as have to save them for the next session. Also I feel hungry and I think they should definitely provide sandwiches.

Female; 40-50's; Bangladeshi

Patient 13

I think the nurses are very good and they do a good deal more than the doctors do. I hardly ever see the doctor and when I do they don't give me much of their time. The doctors change a lot here, now I don't even know who my doctor is. I also think the ward is short staffed. I also think the management of the hospital transport service is not very good. I often have to wait about 55 minutes for the driver to come and pick me up after leaving the ward. However I do think the drivers are very helpful, and always help me get in and out of the car. Getting to the hospital is not as bad, as the drivers often turn up on time but the problem occurs when leaving the hospital.

Sometimes I become hungry and tea and biscuits are not enough to sustain me. I would like to have the sandwiches back as they definitely helped me and also for some people

the sandwiches are their only meal of the day and now they don't even get that. I am feeling really cold and would really like to be given more blankets (she already had three of them round her). The blankets sometimes smell and I would prefer if they didn't smell. My biggest concern is the location of the ward, I am very worried if there was a fire or an emergency of some sort, how would we all get out when we are stuck to the machine- If the patients' wires were all suddenly pulled out, they all would bleed to death. I think putting the ward on the 9th floor was a stupid idea and it should have been put on the ground floor.

On one occasion after finishing the dialysis session I was feeling very hungry, and I was asked to see a doctor 30 minutes later, so I thought I would go to the canteen and get a bite to eat before seeing the doctor... it took me about 20-30 minutes to find the canteen on the 5th floor, by the time I found the canteen I only had about 5 minutes to eat as had to be back on the ward to see the doctor- I think the layout of the new hospital is too complicated, there needs to be better signs to direct patients.

Female; 50's; Black African

Patient 14

I am really hungry and would like the sandwiches back as the tea /coffee and biscuits are just not enough. The doctors and nurses are great; however I think there should be more nurses. I prefer the old hospital as it was warmer and this one is freezing.

Female; 50- 60; Bangladeshi

Summary of Patient Feedback (Common Themes)

- Generally most of the patients are happy with the nursing and clinical staff; they view them as caring and supportive.
- Almost every single patient said that they feel either 'cold' or 'freezing' when they are attached to the dialysis machine (from our observation some patients were shaking because they felt so cold). Patients feel the temperature of the ward needs to go up a lot more to make them feel at ease.
- Some patients mentioned that there was shortage of blankets in the ward; when patients feel cold and request additional blankets (request could be 1-2 blankets extra), the nursing staff are unable to provide them the blankets (some nurses citing that they have to keep them for other sessions) - this causes further discomfort for patients as they do not have enough covering to keep themselves warm.
- Patients feel that the unit is short of nursing staff; they feel insecure that there is a lack of presence of nurses and have cited that they fear if two people 'crash' at the same time there will not be enough staff to help them. They also feel the nurses are overworked as they have to attend to substantial amount of patients.
- Most of the patients said that they were 'hungry' and that tea and biscuits provided were not enough, they feel they should be provided sandwiches as well. Some patients said sandwiches were provided in the past and recently they stopped giving patients sandwiches.

Inpatient Ward - Renal Transplant Ward (9F)

Patient 1

I have been here for over one week and I think this is a very good hospital; the nurses are good and the doctors are very good, the doctors give good advice and information - overall the nursing and clinical look after you well and seem to be caring. There is always a staff member in our bay and I feel there is sufficient staff presence to keep me feeling safe. I

also like the size of the bays, usually at hospitals everyone is cramped into one big ward, but at this hospital there is plenty of room to move about. The food is ok; I can choose what I want.

Male, 50's, White British

Patient 2

So far my experience here has been good; I have been here for the past two weeks and will hopefully get discharged in 10 days. Nurses are ok; they respond to your needs and will do their best to come to your bedside if required, they also seem caring, I would say out of 10 nurses eight are caring and two are ok. In regards to the doctors, well you need to ask a lot of questions before you get answers, some of these doctors think us patients don't have the capacity to understand medical information about our health conditions. I noticed if you ask lots of questions they tend to be helpful and do explain things properly, but they are not forthright with the information.

The bays are clean and the toilets are also clean, however I have noticed the floor does not get cleaned properly as all they do is circle the cleaning machine in the centre of the bays; and don't bother cleaning around the bedsides.

The food is not very good and it's something I would not recommend. They do give you choice, but the menu is not varied.

Male; 50's, White British

Patient 3

I have been in the hospital for 10 weeks now and I had an operation two weeks ago; currently I'm unable to walk due to the nature of my problem and the operation. The overall experience here has been good. There have been numerous occasions since I have been here when the ward was short staffed, due to staff shortages sometimes I have not been given my dinner as I have been unable to walk to get my dinner from the ward corridor. I think this is not right, nurses should be more organised and decide who does which shifts.

I think doctors do their jobs well I always understand what they say and I feel as if they really care for me in a special way. They are friendly and loyal, and I feel I get excellent service therefore I'm very happy with the doctors.

Currently I am waiting to be moved to rehabilitation, I think the process of being transferred to rehabilitation is quite long and I would be happy if they could speed up the process if it is possible. The food provided is not bad I'm more or less happy.

Female, 60's, African

Patient 4

I'm in hospital for my kidney; I had a transplant just 12 days ago. I got a call from the transplant team 12 days ago saying they have found a match for me I then came in hospital in the morning and had the operation, I think this service I received was very fast and quick and efficient. I'm really happy with it.

The service I am getting here at the moment is satisfactory and not the best- it's ok. I think the care I'm getting from doctors is great - I'm very happy with it. There are days when the ward gets short staffed, this creates problem as there is not much interaction

between patients and staff. As I've just had a transplant I'm in a lot of pain all the time, when I need painkillers' nurses take an awful long time to come to me and physically give me medications. I think this should to be improved as soon possible because I think it's not good for patient's prognosis.

As I need ongoing dialysis I've realised when I go off for the treatment my food gets delivered to my bedside by the nurses, and by the time I get back its stone cold, I've asked for them to reheat the food but nurses tell me that it won't be possible as the kitchen is now closed. I am very unhappy with the bedside service and I think it is rude and unacceptable. I'm in hospital for a reason and patients have the right for some courtesy and kindness.

I have noticed that the care I receive over the weekend isn't as good as the care I receive on the weekdays; I understand that not everyone works on the weekend but it's no excuse for quality of care to drop. I think this is a bad mark on the hospital as a whole and this needs to improve for the sake of patient's safety.

Female, 55+, White

Patient 5

The quality of care and service is ok; I've been in hospital around a week now with kidney and bladder problems. I sometimes give the nurses a call (buzzer) but have to wait till at least an hour before someone responds. One night I was in pain and couldn't sleep all night and I ended up waiting for a long time before a nurse came to see me.

I get a visit from the doctor everyday and I think they explain everything I need to know in details and also in a way that I understand properly.

The food here is very bad, the hot food is tasteless and it's not up to standard, therefore I am unable to eat it. For the past three days I have been eating cold sandwiches which do not have much flavour or taste.

Female, 50's, Pakistani

Patient 6

The patient couldn't speak English, so her carer (daughter) gave us her feedback:

I am very upset about the care being provided to my mother. My main concern is that I don't actually feel my mum is safe and I worry that the nurses don't check on her enough or take good care of her. My mother is extremely frail, partially deaf, and partially blind she gets extremely distressed when the nurses don't always come at her demand and when they do eventually come, they just tell her to do it herself. I think the ward is short staffed and the old hospital was much better as there was a good amount of staff there. However I do think the doctors are brilliant.

When I came into A&E a week ago with my mother we were transferred to the RAU (Rapid Assessment Unit) and from the time we came in we had to wait 10 hours to actually be seen by a consultant, even though my mother was in a visibly ill position. By this time it was the evening and for anything to actually be done or to be seen by the specialist consultant they now had to wait till the next morning- this was not a good experience.

I like the new hospital as it is a lot fresher and cleaner, but I think the room (bay) has no air conditioning and it can get very stuffy and hot.

Female; 70-80, Japanese

Patient 7

I have been in hospital for about six days (Kidney transplant operation); I think the care I have received has been fantastic- I am very happy.

From a personal perspective I felt more comfortable coming in for my operation on a week day, as the after care is supposedly better since there are more doctors around then, rather than if the operation was on the weekend. Therefore I was pleased that my operation was on a weekday.

My only complaint is when I was at the HDU (High Dependency Unit) the temperature was “hotter than the sun” and it was totally unbearable. I did understand for anaemic patients the temperature had to be high, but I thought that I should have been placed in a different area.

I think the food is “ok”, but I wouldn’t choose to have that food at home. I think the system of ordering the food you want the day before is pointless and creates wastage i.e. some patients will order their food for the next day but will then get discharged that evening and so the whole meal goes to waste. I think it would be better to order the food in the morning.

Male; 30’s; White

Summary of Patient Feedback (Common Themes)

- Patients generally seem happy about the care and treatment provided at renal inpatient and it seems patients are appreciative that the unit makes all attempts to help patients overcome their kidney issues- therefore it would appear patient’s value the service.
- On the whole most patients feel that doctors and consultants explain things properly and are willing to give them time.
- Most patients feel the ward is ‘short staffed’- patients have cited that the ward lacks staff presence and that if you call the bedside buzzer it takes a long time for nurses to respond or due to lack of staffing some patients are deprived of meals as they are unable to get up from their beds and are dependent on nursing staff to bring the food to their bedside.
- There are mixed views about nursing staff; some patient’s feel some nurses are not supporting their bedside needs and can become rude when patients make requests and other patients feel the nurses are caring and attend to their needs.
- There are mixed views about the food provided- some patients commented that they do not like the food due to blandness of taste and lack of variety on the menu and other patients feel patients should not expect too much from a hospital- therefore the standard is ok and at least you are given a choice to choose from the menu.
- Some patients mentioned that the care and level of staffing over the weekends is not sufficient.

Summary & Recommendations (for all three services visited at the Renal Unit)

- During both visits the majority of the patients that we spoke to seem generally happy with the service they receive from the Renal Unit; they feel staff are caring and the level of treatment and care provided is generally good. As this is a specialised unit patients seem to appreciate the commitment of the unit to support them in managing their condition or help them get better. Conditions related to the kidney can be a long term condition for most of the patients (especially

Haemodialysis patient), it would appear these patients seem well integrated into the unit and have developed supportive relationships with nursing staff.

- We would strongly recommend that patients at the Haemodialysis Unit should be offered sandwiches or some additional food to help them overcome their hunger (if required). When speaking to patients it was evident to us that some patients were really suffering due to being hungry- this was very uncomfortable for us. We would recommend that additional food being offered is provided on an individual needs assessment, we particularly observed that the patients that were generally hungry were elderly or frail; living on their own or possibly falling into the category of 'low income'.
- We would suggest that the room temperature of the Haemodialysis Unit is 'balanced' so patients do not feel cold to the point they start to shake due to freezing. If it is not possible to balance the room temperature of the ward (could be due to valid reasons), then we would recommend that the ward has sufficient blankets to cover everyone's requirement.
- Staff shortages (or lack of staff presence) have come up often in our discussion with patients; we would strongly urge the unit to review the staffing levels to tackle the issues/fears highlighted by patients.
- There needs to be better promotion of the 'Renal Patient Group' and generally better engagement with patients (especially the Haemodialysis Unit patients). Most patients are not aware of existence of the patient group and patients feel they are not involved, this is reflected by what one of the patients we spoke to said 'I have been coming here for 8 years and not once has anybody asked me what I want'.

Questions for Renal Unit Management

- Patients at the Haemodialysis Unit are feeling discomfort due the fact they feel very cold, what actions (if any) are possible to overcome this?
- What is the protocol on blanket distribution at the Haemodialysis Unit? Is there a limitation on how many blankets one patient can have?
- Patients at the Haemodialysis Unit are also feeling discomfort due to feeling 'hungry'; it would be useful to know why the sandwich provision has been withdrawn. And how the unit plans to tackle the issue of hungry patients?

Healthwatch Tower Hamlets representatives and staff would like to thank Dr Neil Ashman and Brenda McManus and their team for making all the necessary arrangements in organising the visit and for helping us during our visit.

DISCLAIMER:

1. The observations made in this report relate only to the visit carried out at the Renal Unit on the 28th September and 09th October 2013, which lasted for 2.5 Hours on each day.
2. This report is not representative of all patients/service users/carers. It only represents the views of those who were able to contribute within the restricted time available.

Appendix 2

Enter and View Visit

Royal London Hospital - Fracture Clinic

Barts Trust

2nd Floor, Fracture Clinic, Royal London Hospital, Whitechapel E1 1BB

Date: Friday 30 August 2013 10.00-12.30 & Wednesday 23rd October 10.30-12.30 (Two visits)

Healthwatch Tower Hamlets E&V Representatives: David Burbidge; William Colverson; Julia Avery

Healthwatch Hackney E&V Representative: Milan Seth

Healthwatch Tower Hamlets Staff: Shamsur Choudhury & Lindsey Williams

Barts Contact: Pramod Achan (Head of Department) & Hayley Terry (Head of Nursing Orthopaedics)

Purpose of Visit:

1. To ascertain feedback from Fracture Clinic patients on their experience of services at the Fracture Clinic.
2. To find out from patients their suggestions for improving the service at the Fracture Clinic.

The visit to the Fracture Clinic was undertaken over two days, on the first visit Healthwatch representatives spoke to Fracture Clinic management and to patients attending the 'Back Clinic'. We decided to undertake a further visit to the Fracture Clinic (23rd October 2013), as (1) on the first visit (30/08/13) there were not many patients in the clinic at the time of our visit and (2) we wanted to gather feedback from a diverse range of Fracture Clinic patients rather than only 'Back Clinic' patients.

General information on the Fracture Clinic (based on observations and factual information provided by management)

- The Fracture Clinic is part of the Surgery CAG and sees 9000 patients per year. They provide the following services: One Stop shoulder clinic; pelvic and acetabular; fracture; sports hip and knee; limb reconstruction; spinal deformity; bone infection; major trauma follow up; foot and ankle; and complex hand.
- The Fracture Clinic see patients from all over the country with the majority of patients coming through A&E.
- The Fracture Clinic has a large waiting area that is divided into two sections. The smaller section is for patients waiting for x-rays and the larger section is for patients waiting to see Consultants/Registrars. Some patients (depending on injury type and stage of rehabilitation) are required to have an x-ray first and then wait to see a Consultant, for these types of patients the whole journey could last a minimum of 3-5 hours per visit.
- The main reception area (located in the larger waiting area) has a TV screen placed on the wall behind the reception staff; the TV screen displays adverts and in quite small writing at the bottom of the adverts it states the waiting time delays for Consultants. It is important to highlight that the TV screen is not visible to most of the patients in the waiting area.
- On the day of our visit the leaflet racks were also empty and we could not find any service leaflets in either of the waiting areas.

- The Fracture Clinic has a 23% response rate of patients completing the 'Friends and Family Test'- this is a good response rate compared to other Bart's departments (CAG).
- Patient Engagement: there are four patient reps on the CAG Board (non executive board members).

Current Challenge

- There is a significant backlog in orthopaedic surgical treatments; most patients that require surgical treatment have had their operation delayed by at least six months. The main reason for the backlog has been the departure of several specialised consultants in 2012 and as a result the department has had to recruit suitable replacement consultants. As orthopaedics surgery is a highly specialised medical discipline, Dr Achan said that it has not been easy to find suitable candidates. However in the last few months they have recruited and trained new consultants and the backlog is being tackled by undertaking extra clinics in the evenings and at weekends. By December 2013 it is anticipated the backlog will be cleared.
- on the day of our first visit we noticed a few patients getting frustrated with their appointment arrangements, these patients told us that their appointment letter had incorrect information about their appointment time and location therefore they had had a wasted visit or missed their appointment slot as it was at another location. We asked Dr Achan if this was a common occurrence, Dr Achan reconfirmed that this scenario happens frequently and some patients turn up for their appointments on the wrong day, wrong time or at the wrong location (i.e. their appointment might be at St Barts). He highlighted that this is quite frustrating for the team as they have no control over the administration of appointment letters as they are sent by the Central Appointments Team and it would appear that they make a lot of mistakes.
- Some patients have to wait longer for their appointment as their x-rays/scans have not been sent by their GP or their GP had not informed them that they need to contact the organisation that performed the x-ray/scans (In-Health) to transfer them to the hospital. Staff are then required to request x-rays/scans from In-Health on behalf of the patient and this process can take up to one hour- this whole process increases the patients waiting time and also increases the administration of the team.

Patient Comments /Feedback

Fracture Clinic - Friday 30th August (Back Clinic)

Patient 1

I'm happy with the service so far and I have no complaints.

Female, 50's, White British

Patient 2

The Clinic is running 10 minutes late for my appointment but that's fine and I don't mind. The environment is clean and the staff are friendly.

Female, 40s, White British

Patient 3

I've not been here for a while as I have spent the last two years trying to get an appointment for someone to resolve my lower back problems - the only reason why I was seen today was because I went through the Complaints' Department. I had my surgery in August 2011 and was seen six weeks later by the Physiotherapy Department (London Royal Hospital) and was told that I will receive an appointment at the Pain Clinic at Mile End Hospital. I waited for a couple of weeks, but never received an appointment. I tried to chase-up my appointment, just to be told that I missed it (this bearing in mind I never received the appointment letter in the first place). So far it's been a bit of a nightmare to get an appointment...

Female, 50s, White British

Patient 4

My appointment was at 10.45 and it's now 11.20am. Apparently they are trying to retrieve my MRI scan. I don't know why they don't have it already? Apart from that the service is fine.

Female, 30s, Bangladeshi

Patient 5

It's my first time here and I have been referred by my GP, I waited about three-four weeks to get this appointment, which is quite good for a hospital appointment...so far everything seems ok, receptionist has been helpful...not sure about waiting times though, but I did not notice the waiting times information at the bottom of the TV screen until you pointed it out to me.

Male; 40's, White British

Patient 6

This is my first appointment in two years; my back is troubling me again, it has taken a lot of pleading to the GP to refer me again-almost nine months!! Staff seem friendly here, however my appointment is running 40 minutes late and also I don't know who I am seeing today, it would be useful if receptionist informed me when I checked in if consultants are running late and also provide the name of the consultant I will be seen by today.

Females; early 40's, Bangladeshi

Fracture Clinic- Wednesday 23rd October 2013

Patient 1

I came into A&E after my accident. The nurses there were extremely attentive and caring; I really appreciated the help they gave me. Whilst at A&E I was seen by three different doctors who gave me three different diagnoses within the space of 24 hours. I understand that they were trying to get information to me as quickly as possible but I think doctors need to communicate with each other better.

I have been to the fracture clinic three times now over 4 months to get scans, and really feel that waiting so long for the next scan is a waste of time. I am not too sure what I should be doing in-between as no one really tells me. Every time I come for a scan I see a different doctor and feel there is no continuity. I would like to have access to my medical record much more easily, like you can in the US, so I can really see what is going on. I have now been to see a private doctor who really explained to me everything properly and talked me through useful exercises to do in the mean time. I always leave the Fracture

Clinic feeling very happy but do sometimes feel incomplete as if they haven't put all the pieces together. Waiting times are usually not a problem here, although today my appointment was 9:15 and it is now 10:16am.

Female; 30-40, Mixed background American

Patient 2

I was referred here by my GP, which I feel was a very easy process with not too much hassle. I initially went to the hospital in Harlow for my operation, but was then referred here for all the scans. The doctors and nurses here are absolutely fantastic, they come when you call them; they are also attentive and if they see you feeling down they always try to cheer you up. My only complaint is that there is no parking at the Royal London Hospital.

Female; 70-80, White British

Patient 3

I was initially taken to the A&E in Newham. I did not like the care I received there as I felt the doctors and nurses were not caring enough. I have preferred the care here, I feel the doctors and nurses are much more organised and they actually know what is going on. With regards to the waiting time, it is not usually that bad, and I do not know today how long we will have to wait. I hadn't noticed the screen that informs a patient of possible delays until it was pointed out to me by you and also the receptionist has not told me either. We would like to be told by the receptionist for possible waiting delays as we would need to go and put another parking ticket on our car otherwise we could get a parking fine. Sometimes I get annoyed by the double standards of hospitals for example if we are late for appointment our appointment gets cancelled and we have to wait another four weeks to be seen, but the irony is...doctors are allowed to be late and that's not a problem!!.

Male; 20-30, Asian

Patient 4

I came in through A&E, the doctor, who I can't remember the name of, was very rude and arrogant, but I made a complaint and was told I didn't have to see him again. The nurses here on the Fracture Clinic are really good, they definitely look after you well, they are very caring and are genuinely concerned. The Clinic does not usually run late, but today it seems they are running late by thirty minutes. I cannot think of anything that I would like to change about the service.

Female, 20-30, Mixed Origin

Patient 5

After my accident I had to wait three weeks for my operation, but it was initially going to be five weeks, but as they could see I was in a lot of pain the consultant found me a slot and operated on me sooner- I am very grateful for this. Within the first minutes of seeing the doctor I felt at ease as they are very polite and kind and Dr Elvey is fantastic. All my appointments have been pre booked for me and I was just told when I have to come in... It couldn't have been any easier. Also the care provided by the nurses was fantastic, they really looked after me.

Male, 50-60, Asian

Patient 6

I was referred here by my GP; I find the waiting time delays can be very annoying. To get an appointment here was relatively easy, however to get an appointment with physio is an absolute nightmare and I believe that the Physio Department is definitely a downfall. After my operation I was on a ward for seven days, on three of the days I didn't get the food that I ordered, on one day I got no food at all apart from sandwiches, and I certainly don't want cold food when I'm in hospital. Out of the seven days I was on ward, only on three of those days I got the food I ordered, and even then it really wasn't very nice. I also think the design of the new lifts is extremely bad as a lot of people don't realise that on some lifts you have to operate them from the outside, so you have people going up and down constantly and looking confused.

My biggest complaint however is the parking...there is just nowhere to park, I have a disabled badge and although there are some disabled parking bays they are always full- we live in Essex and we have to drive in because we can't get the tube as Whitechapel underground Station does not have lifts or escalators and using the stairs is not possible due to my injury. They really should have designed a car park when they made the new hospital. Also we were not given any information on parking by the Fracture Clinic- it would have been useful if they provided this information to us.

Male, 50-60, White British

Patient 7

I came in through A&E. Although I had broken my leg, I had to walk down the ramp to get to A&E as I was told if I wanted a wheelchair I would have to wait longer- this I did not want to do. This is my first time at the Fracture Clinic, and they are running an hour late...I never understand why the doctors are running late they should just employ more, and I don't believe that they have no money. The parking situation is ridiculous, I am very lucky as my partner is a postman and so we can park in the post office car park that is right next door. I don't know how anyone else finds a place to park here.

I often bring my children to the Out of Hour's service, I went there the other day and was told to go home and then call them to get an appointment, even though I was standing right in front of them, The Out of Hours service is also very far away from the entrance, which I don't think is ideal.

Female; 37, Turkish

Patient 8

I came in through A&E. At A&E I initially saw someone very quickly, but then to see the specialist I had to wait for four hours. My operation has been cancelled four times, and they usually tell me about the cancellation only the night before, this meant all my plans constantly got ruined and I just couldn't plan anything- I think the surgery referral process is very bad. The doctors and nurses are great though; they are polite and not rude...Mr Culpin (Consultant) is very nice. This is my third time here at the Fracture Clinic, the first time I had to wait about an hour, the second time only about ten minutes and this time, well I haven't been seen yet and my appointment was supposed to be fifteen minutes ago.

Male; 20-30, White British

Patient 9

I think the service that is given here is pretty good. I'm originally from South of Wales, but was working in London when I had a car accident; the helicopter flew me to the hospital (Accident and Emergency). This is my one year follow-up appointment at the Fracture Clinic. I've so far attended two follow up appointments after my accident (which is every 3 month), in which I have found the whole process to be quick and effective. In saying that, there were a few issues I was not happy about, for my first follow-up appointment at the hospital, I was sent a private ambulance to pick me up from my home in South Wales, which I felt was nice but was not allowed to have my wife escort me through the journey in the ambulance. In the end my consultants (Peter Bates) secretary had to send an email for my wife to be allowed to travel down with me to London in the ambulance. When I was an inpatient I noticed that the communication within the hospital wards (not Fracture Clinic) between the staff and the patients was not good; half of the staff are not able to speak English properly and could not explain the information on the progress of my treatment. I like the staff at the Fracture Clinic, they are warm and approachable and my consultant Peter Bates is a great consultant as he is friendly; approachable and always makes me feel welcomed.

I also like the new hospital and the location of the hospital; you can get some really great views of London from some of the windows. My only suggestion would be to make staff and patient communication better within the wards.

Male; 50s, White British

Patient 10

I have come here today with my 16 year old daughter for an x-ray; she was involved in a car accident, in which she was admitted through A&E. She is here for her second x-ray follow-up appointment, I have to say I am a bit nervous and worried because I have been waiting here for an hour now (since my daughter got called in) and I am wondering if everything is alright. I'm not too sure how long these things take, but I do think it would have been nice if they stated on the referral letter an estimate time for how long this appointment will take. I think the Clinic staff are welcoming and approachable.

Female; 40's; Bangladesh

Patient 11

I'm here today for my first follow-up appointment after fracturing my arm. So far I have found the staff to be nice and helpful and the environment to be open and clean. If I had one criticism it would be the waiting time, I've been here for nearly 45 minutes and I have not been seen yet. Everything else is pretty perfect here compared to some hospitals I've been to...for example Queen Mary's Hospital is disgusting.

Female; 50's, White British

Patient 12

This is the second time my husband is visiting the Fracture Clinic; he had a fall a few weeks ago and was referred here through the A&E department. Today the ambulance picked him up from our home and I got a train here (which was really nice of them to do). I think the staff here are friendly and informative and I also think the waiting area is open and welcoming and I don't have to wait too long to be seen. I'm happy with the service given to my husband here and he also feels the same way as I do.

Female; 70's, White British

Patient 13

I am here today for my one year check up appointment. I was referred here from Wales. I was involved in a motorbike accident in Wales in which I broke my arm and practically destroyed my elbow. My injuries were so extreme that I was referred to London Royal Hospital because it's a specialist hospital. The only thing I was disappointed about was the process of my referral. I had the accident on a Saturday in which I was admitted in to a hospital in Wales and was discharged the next day and was not seen until the following week at the Royal London Hospital. This meant I walked around with a broken arm for a week. I was also not supplied with any transport and was asked to make a least 3 trips back and forward, between London and Wales, before I had my surgery 4 weeks later. To be quite honest with you, I have found the staff and consultants in the Fracture Clinic to be very helpful when dealing with my queries and if the clinic is running late they usually tell you on your time of arrival. But I have noticed that the clinic runs late most of the time, which can be an inconvenient if you got somewhere to go i.e. work.

Male, 50s, Welsh

Patient 14

I have been here since 9.30am (appointment time) and now its 10.20am and its seems like everyone that came after me is being seen before me- this is making me feel frustrated- I am asking myself why are other patients being seen before me, is it because I am Asian!! when I checked in at 9.30am the receptionist did not make eye contact with me and did not tell me who I would be seeing or if my appointment is running late- she needs to engage with patients better and needs to provide better customer service. I did not notice the screen informing patients of waiting times delays, until you highlighted that to me. It's also taking them far too long to take off my plaster, look at the state of my hand, it turning black!!,I should have taken off this plaster two weeks ago and now I am in my fifth week...I don't understand why it takes them so long to give patients appointments. Doctors and nurses are very good here; I feel they take good care of me when I see them.

Male, 40's, Pakistani

Patient 15

It's my first time here, I had an x-ray at St Barts this morning and they told me to come here, they made the appointment for me...so far the experience has been good; the receptionist has been very helpful...as it's my first time here at this hospital, I found the clinic difficult to find, the signs leading to the clinic are very small.

Male; 20's; White British

Patient 16

It's my second visit here, so far the experience has been very good...on my first visit I was told that I would possibly have to wait 3 weeks before I could get an MRI scan appointment (this scan was required to find out what was wrong with me), then I would have to wait a further 3 weeks to see a consultant to discuss the MRI scan result...but luckily for me on my first visit there was a MRI scan cancellation on that day and they offered me that appointment, I was very happy about that as it saved me three weeks of waiting in anxiousness ...the consultant I saw was very good as he was very through... today I have waited a while, and not sure what time I will be seen.. I am really not that fussed about waiting I am more concerned about my leg getting better. In terms of improving the service...I would suggest they centralise the booking of external appointments (i.e. scans) from the Fracture Clinic,this would make it easier for patients as they would not have to go to a different department to make an appointment, for example if you need a MRI scan

you would have to go the Scan Department, which is located on another floor to make that appointment. Also a lot of people find it difficult to navigate around the new hospital; so if you are asked to go to another department to make an appointment it would be useful if the Fracture Clinic could provide a map with directions.

Patient 17

The service here has been generally alright, I broke my wrist 5-6 weeks ago in Kent, I went to Dartford Hospital and did x-rays, etc, the doctors suggested since I lived in London maybe it would be easier to continue my care at the Royal London Hospital, and they would send x-rays to the Royal London and provide me with all relevant documents to move onto the next phase of my recovery...When I came to the Royal London I was told that no x-ray had been sent and the documents Dartford Hospital gave was of no use to them and I had to do everything all over again (second opinion)- I felt really frustrated that I had been through the whole process and was being held back from getting better as the two hospitals could not communicate with each other.

Its good here, staff are doing their bit to help people get better and I appreciate that all the care I get is free...I like the way different teams (i.e. CT Scans) work together to come up with answers to help patients...for example I got referred to CT scans straight away and got seen within 2 weeks.

Male, 20's, White British

Patient 18

The service here is very good and we are happy with everything, the only downside is the waiting around...

Male; 70's, White British

Summary of Patient Feedback (Based on Common themes and observations)

- Most patients seem to value the care they get at the Fracture Clinic and generally seem to be happy with the overall service they receive- this is possibly due to the important fact that the Fracture Clinic is a 'specialist clinic' and patients all around the country are appreciative of this.
- The majority of patients said that they think nursing and frontline staff at the Fracture Clinic are friendly, helpful and caring and that the consultants are thorough and reassuring.
- Most patients cited 'waiting times' as their biggest grievance, the main issue is not knowing when they will be seen, for example a lot of patients said that they did not know that the TV screen has information on waiting time delays or some have cited that they have not been informed of potential waiting time delays by the reception staff when they checked in.
- Some new patients seemed unclear of the processes they would have to go through on their first appointment i.e. not knowing exactly what would happen next and how long they would have to wait.
- Some patients feel that the Fracture Clinic works well with other departments (i.e. CT Scans) however some feel that the Fracture Clinic should book appointments for them, rather than ask them to book appointments themselves.
- Some patients felt getting follow-up appointments can take a lot longer than expected or warranted.
- Some patients mentioned that parking is an issue as there are not many places to park within the hospital site. Also there are not sufficient disabled bays near the main entrance.

Recommendations (Based on patient feedback and observations)

- Leaflet racks should be placed in more prominent places inside the consulting areas/cubicles; currently they are hidden away in certain cubicles or not easily visible to patients. (Observation)
- Leaflets racks in the main waiting areas need to be monitored in order to ensure that leaflets are always available- on the day of our visit not a single leaflet was displayed on the racks. (Observation)
- Waiting times was the biggest grievance for most patients; it appears most patients were not informed about potential waiting time delays when they checked in with the receptionist and also most patients are unaware that the TV screen has information about waiting time delays. We would suggest that the reception staff actively inform patients about potential delays when they check in for their appointments and also to highlight to patients to check the bottom of TV screen to get updates about potential waiting time delays.
- It would be useful if reception staff can inform new patients what they should expect from the first visit and how long they might be expected to stay. This information can also be provided in a leaflet.
- Most patients sitting in the waiting area are not able to view the TV screen with waiting time information due to the position of the TV screen; we would suggest that the TV screen is put in a more prominent place in the waiting area or there are different methods of informing people i.e. notice board. (Observation)
- Water machines did not have any cups, we was told by nursing staff that cups are available from the reception staff upon request- however if we were not made aware of this by the nursing staff we would have assumed that there no cups available for patients- we would suggest to make this information apparent, there needs to be a notice above the water machine informing patients that all 'Fracture Clinic Patients' can get cups from the reception staff. (Observation)
- We also feel patients should be offered 'choice' on whether they should have the x-ray and the consultant appointment on the same day; some local patients might not want to wait 3-5 hours for the whole process to conclude on each visit.
- We would also suggest that 'Appointment Letters' be sent with information on the process & procedures of seeing patients at the Fracture Clinic (so there are no unexpected surprises); potential waiting time delays; information about parking and a map of the hospital.

Appendix 3

Enter and View Visit Oncology (Rahere - 5B Ward) St Bartholomew's Hospital Barts Trust

Date: Wednesday 2 October 2013; 10.00-12.30pm
Healthwatch Members: Kate Melvin and Matilda Joseph
Healthwatch Staff: Dianne Barham
Barts Contact: Claire Murrell Head of Nursing, Cancer CAG

Information that triggered the visit

- poor national cancer patient experience survey results for 2012
- the experience of four women in Tower Hamlets and Hackney who had used cancer services in the past twelve months.

Purpose of the visit

To follow up with staff and patients themes that had been identified from patient feedback including:

- adequate nursing staff on the ward particularly at night
- caring and compassionate staff
- staff turnover and morale
- patients understanding and being involved in their care
- pain management
- the environment
- support and aftercare

Conversation with Head of Nursing for Cancer, Matron of Day Ward and Matron of Rahere Ward:

St Bartholomew's is a specialist cancer service that covers the majority of cancers including breast, cervical, testicular as well as leukaemia and lymphedema.

The majority of breast cancer surgery is now done as day surgery. This can lead to some patients feeling as if they are being 'rushed' through. It's important for the hospital to think about how they can manage patient expectations and to support them to be prepared for what is going to happen on the day. The hospital is able to offer overnight accommodation in a hostel 'Gloucester House' for people travelling longer distances so that they can stay the night before as it is a 7am start.

Staff felt that the poor national cancer patient experience survey results do not reflect the work that has been done by the new Cancer Clinical Academic Group (CAG) which came into effect in October whilst the survey was conducted in September. We would hope to see some real improvements next year then. London hospitals all perform poorly in the survey.

They are also struggling to reach the target of a 15 percent return on the friends and family test survey. They may be able to use volunteers to focus on carrying out the survey to improve the response rate.

The staff were questioned as to whether the rumours were true that clinical nurse specialist or 'cancer nurses' as patients call them, were being made redundant. Staff said that there was a current proposal to reduce the Cancer Nurse Specialists by 20 percent. In our patient interviews these people were consistently singled out as providing vital support and was where they went for information and reassurance. Indeed they were seen as being essential to cancer care services.

The ratio of nurses to patients is currently one to five. However, the consultation currently being undertaken in light of the financial review is suggesting that this be reduced to one nurse to seven patients. Again given that our feedback had highlighted that patients already feel that there are low staff numbers particularly at night. We feel that this would impact on patients feeling safe and indeed on being safe. This is below the rate at similar hospitals and comparable cancer centres. If there were staff shortages or illness this ratio could easily fall to one to ten.

We asked what impact this was having on staff morale and were informed that staff were leaving to take up jobs in other Trusts and that they have a high vacancy rate. They can use bank staff rather than agency staff to meet any gaps but they are generally not cancer trained nurses.

High turnover rates may also be due to the patient mix on the ward with a wide range of cancers and treatments, a mixture of short and long stay patients and oncology and non-oncology patients. This was clearly challenging as they require different skills mixes and you may have the 'dying' next to the 'surgical patients'.

There can be issues with providing cancer care across several sites and cancer patients can end up being cared for on general surgical wards. They are offering training to non cancer nurses on cancer care where appropriate. Unquestionably the feeling from the staff was that nurses on the oncology wards needed to be cancer trained.

They do try and 'individualise' the care as much as possible and commented how they reminded nurses to use people's names and not their bed numbers.

The cancer nurse specialists were also seen as being key to patients being given information at the 'right' time and at the right level. However there was some feeling that this could deskill the ward staff and may be impacting on their giving all round care.

Patients are invited back to the Health and Wellbeing clinic after a few weeks but staff did not seem to be aware of the full range of aftercare programmes such as Cancer Kin, 'Transitions' or the Survivorship Education Programme which were highly valued by patients who knew about them. We are not sure why they are not better promoted to patients on the ward.

Visit to Tunnel

We asked to see the 'tunnel' through which patients travel on their way (but not usually on their way back) from surgery and about which there had been complaints. The following was observed:

- It was extremely 'hot' and 'stuffy'
- The paint was falling from the ceiling

- There were large patches of damp on the walls and ceiling
- The wires were not 'encased'

Nonetheless, it didn't seem to worry the Matron that this is what patients see immediately before they go into surgery. It certainly didn't give the impression that they are going to a hygienic and germ free environment. We accept that this part of the building is due to be demolished and any maintenance is likely to be a waste of very limited resources but perhaps some apology and explanation could be provided and reassurance. If possible it might also be important to reassure patients that it does not pose a health risk.

Rahere Ward

The ward cares for women with cancer including gynaecological, breast and bowel surgery; chemotherapy or radiotherapy and palliative care. They also care for non-cancer fertility surgery. Some people can be there for less than 24 hours and some can be there for two to three months. As noted above this mix can make it difficult as the different groups require different nursing skills.

There are 22 beds: three rooms of two, two bays of four and individual side rooms.

General comments

This is a new ward and appeared clean and tidy and also patients observed did not complain about this.

There were wide spacious rooms and large bathrooms. It is well equipped with one patient commenting, *"It's like a hotel in here. I've been private before and it wasn't as good as this"*.

However, the new wards have the potential to leave patients feeling isolated which leads to them feeling unsafe and increases anxiety. Even if the nursing levels are the same as the old wards it feels like there are fewer staff as they are unable to keep an eye on a large number of patients at once and they are less visible to patients. You lose the sense that 'nurses' are always around.

We didn't get the sense the protected meal times were being observed. One patient was eating their lunch and was spilling it all the way down her front. The Healthwatch representative helped 'clean' her when requested. The representative also mentioned that the woman was having difficulty to a member of staff (presumed to be a nurse) but the nurse appeared to just shrug.

The Healthwatch representative was also asked to draw the curtains to let in light. It appeared the staff had not considered this to be important for the patients.

The date on the staff on duty board was wrong so we were not sure if they were the staff on at the time.

There was a really lovely patient/family room with a TV, coffee and tea making facilities and leaflets and information. It appeared they only had thin plastic cups for the tea and coffee and not polystyrene.

Talking to patients

Patient A:

White English Female - aged 84, lives in Tower Hamlets, diagnosed with bowel and colon cancer accompanied by a clot on the lung. Her son attended the interview.

Brief summary of experience: Was diagnosed in May. GP originally thought it was IBS but following tests discovered it was cancer. Is presently having chemotherapy tablets to shrink the cancer and is also having treatment for the clot. The clot was discovered when she had a scan. Family were impressed that they were phoned within an hour of her going home after the scan to be told there was a clot on the lung.

General attitude was they are *'doing the best for me'*. The care has *been good*. 'She felt she and her family had been *'told enough'* and the son agreed. There have been *'no delays'* at any stage and there were *'very good staff'*.

Considers the food to be *'good - they give you too much and can't eat a lot'*. She also commented that the *'ward is cleaned every day and on top of everything too'*

She also considered that the different parts of the healthcare system *'work well together'* and they *'wouldn't change anything'*.

Overall very appreciative of care.

Patient B:

Afro Caribbean Female, 47, from Hackney, diagnosed with an UPS (unknown primary). Also has **Myasthenia Gravis** (MG) - an auto immune disease

Summary of Experience: Had back pain, went to outpatients, was told it was a trapped nerve. Had to go to emergency GP, received stronger painkillers. Own GP subsequently gave blood tests, x ray and all 'negative'. Again a week later was told that all her bloods were 'negative'. Still believed it was a trapped nerve and told to *'keep moving'*.

Three weeks later, on the phone to a friend, *'tearful and not sleeping'*. Friend said go to hospital as believed it couldn't just be a trapped nerve and back pain. By this stage, she could not walk.

At the Homerton she was then kept in as the pain was so bad. The physios came and gave her more painkillers. Had an MRI Scan - *'the toilet roll tube one'* but was *'classed as non urgent'*. They discovered she had a compressed fracture of the disc. Then had a further scan a few days later - *'again the toilet roll tube one'*. Results showed she had two compressed fractures and two hairline fractures of the ribs. Further tests then revealed that she had bone cancer of pelvis, ribs and spine but not known where the primary is although they now think it is *'hormonally based and had spread into the bones'*. (She believed she would receive the results of further tests on the day of the HW visit) *'Hopefully someone will sit me down and tell me what is what'*

'(Being told you have cancer) is the worse news ever but for the want of a better word, it was made not the worst time in my life', because, she said, of the good treatment in the Homerton.

She was then actually told she had Stage IV cancer by a doctor (Dr Sloane) at the Homerton - she was not expecting this news and thought it was just a routine consultation.

Diagnosed with MG at the age of 20, she had been seeing a consultant regularly. Before she had been diagnosed with cancer and when she was not feeling well with her back, she had told the consultant for the MG, Dr Radanovitch, at Barts repeatedly that something *'was not right'* but he had not listened. She feels more upset with him because of this since she

believed it delayed her diagnosis. She is less resentful of the GPs since the blood tests had all been ok.

Following the news, she was told that she had to go to Barts *'immediately for treatment as it has to start sooner rather than later. I was freaked with the news - end game and all that and I was just told I had to start treatment immediately'*

She was given a 'bone strengthener' and was transferred to Barts without being consulted at all. She was transferred immediately on the Friday - *'I felt picked up and dumped here. Patients waiting to go home have to wait longer than that. I was given no time to breathe and I know people can have Stage IV for years'*

Far prefers the Homerton. In Lamb Ward, at the Homerton, her experience had been *'good, easy and was kept informed'*.

She said she *'feels as she has been kidnapped here. I don't want to be here as I did not make the decision'*.

'On Monday (this week) I was told that I would have the bone strengthener and the tablet but I didn't know what the tablet was for. I have been given no choice of different treatments'. However, the Clinical Nurse Specialist brought her information and she was told she could ask for more.

Given she also has a MG nurse who is based at UCH, she phoned her, who reassured her that she could take the tablets with her MG medication and condition. But, she says: *'I feel as if I have been Shanghai-ed - no-one explained what type of treatment. I was just sobbing. I was just not consulted about the treatment'*. Suggested that she should complain which she did and had a meeting with the Matron, Registrar and nurses. However, she feels, *'she has not been listened to'*

'I was also not asked whether I wanted treatment at all'

She is upset as she would have far preferred to stay in the Homerton where her family and support network could visit.

'I had a hissy fit and Brian this junior doctor came - and did he have an attitude - a major attitude. And he just said, so what is so special about the Homerton then? But he did not understand that my people can come in their lunch hour or drop in some food'

'And what I don't understand is that I am having medication first and then chemo and then radioactive stuff - so if it is just medication, why can't I stay in the Homerton? And all I am told is that it is the best place to be. I would have been happy at UCH as my (MG) nurse is there. The choice was taken away from me'

Does not feel 'safe' in Barts and *'I just don't feel comfortable. I feel there is an ulterior motive - why was I transferred so fast? And they said I had to have this treatment there and then and this is where they treat people.'*

She comments, too, that the staff on the ward are variable. When she arrived she asked for some diapers and she was told by a nurse that they had run out - *'the nurse just shrugged but then I asked someone else and he found me some'*. She thinks that some of the staff are just 'lazy' but, *'there is also not enough staff here. They do come when you call them but in the evenings they are busy.'*

'It is clean'

'Food is like pre-school portions'

'There is no privacy - people poking their heads around while getting washed. Curtains are closed for a reason but they still do it. I feel vulnerable here like Alice in Wonderland being picked up and dropped'

However she does feel that generally her care has been well co-ordinated between different branches of the care system.

Patient C

White English Female in her 70's from Tower Hamlets.

She said that the *'nurses were marvellous' the food is good and you get a good choice.*

The GP had referred her to the Royal London after she had been getting bleeding like the end of a bad period. Royal London found polyps on her ovaries but because the ovaries shrink as you get older they weren't sure what is was. Perhaps a cyst on her ovary. When she went to have her MRI examination they found her sugar was high. She was sent on to St Barts for further investigations and she was waiting for tests. She had been here for three days. She hadn't had any problems with waiting times or delays in her treatment.

A doctor had come in the day before and started talking about her breasts -they had the wrong patient notes! However she had been worried about a lump on her breast for a while which her GP hadn't checked properly she felt so the Doctor gave her a thorough examination, said it was a blister and that they would remove it for her later. This had put her mind at rest.

One of the nurses - Steve *'was very nice and helpful'*. Staff were also fine at night time and she had been sleeping very well. *'Whatever you want they help you with'* She's been in a lot of hospitals and *'they're more efficient than any of them'*

She is a patient at Gill Street Practice in Tower Hamlets *'is good but you never get seen on time. You show up for a ten o'clock appointment and don't get seen until twenty to eleven' Dr Livingstone was good but she's left now. I have Dr Vickers now who is good and there is a good practice manager.'*

'Our pharmacy has also been good. The GP sends my prescriptions there and my husband goes and picks them up' Nash Pharmacy on Commercial Road.

Patient D

White English Female, 92 years old.

She was very happy with her care and was being discharged today and was sitting waiting to go home. She had been in the ward for six days. The GP had organised a blood test at the beginning of July because they thought she was anaemic. She said there were no delays in her treatment but then she said *'I came in for the operation the first time but they said they didn't have enough nurses for aftercare so they sent me home again'* But she was back in within the week and they did the operation.

'I have a key worker who is personal to me - which is very helpful. She has been in twice to see me and I can call her whenever I need to'

She said the nights were also ok.

'The food is good for hospital food and you have a good choice, mind you I'm always a good eater'

She didn't have any problems with the pain management and said that she was able to manage her own medications for her other conditions well while she was in the hospital.

She wasn't worried about her discharge home as all thought she lived alone she had a son and friends and neighbours who would look after her.

Patient E

Young woman late 20's early 30's *Leytonstone, Middle Eastern*

'I went to Whipps Cross A and E on the Bank Holiday weekend and they expected that I had appendicitis. I was referred for an ultrasound on the Tuesday or Wednesday. On Saturday I had MRI scan. Wednesday the MDT came back and I had the operation the following day.'

'I was referred to a nurse oncologist but nobody had mentioned that I might have cancer. It seems that they want to keep you calm and not worry you but it would be better if they were more honest. It would have been better if they had said that there is likelihood or it's very likely that you've got cancer.'

She didn't really feel that she had time to understand or be involved in her care as it all happened so quickly. *'I didn't have time to think or to do any research - they just said they had to get it out'*

She felt that she would need to have psychological help or counselling after the treatment *'I can't wash myself as I can't look at my scar. My sister helps me'*

She felt that the nurses were good but that there was a shortage of night staff. *'The day after my operation I was high on morphine, firstly I didn't know where the alarm was and when I did find it I couldn't get to it. I couldn't see the nurse and nobody came in. In the end I called my family on my mobile phone to get a nurse to come and see me. The staff are very helpful though'*

She felt her pain was managed ok but she had a lot of vomiting when she went on the oral painkiller.

'The food is awful, not appetising and bland. The halal food is always curry. Not all Muslims are south Asian and I don't like the curry. I'd rather have non-curry, something like a halal chicken sandwich or lasagne. Sometimes I have the kosher. It's like having aeroplane food'

Other observations

Someone's patient notes were left out on the reception desk while we were standing there with the desk unattended for at least 5 minutes.

Conclusions

There was a sense from patients that decisions were made and actions were taken so quickly that they did not have time to take in information or make informed decisions. All though they could see the potential benefit of quick action it also seemed to leave them in a state of shock and struggling to cope. It seems that aftercare is especially crucial to this group and sympathetic nursing with the capacity to perhaps take more time to explain to patients what is happening.

With this in mind we feel that it is very, very important that nursing ratios are not cut in the cancer service. As noted there already seems to be issues with patients feeling safe at night and staff morale and staff vacancies are already at a critical level. Clearly, one of the factors that differentiated between those who felt 'safe' and those that did not, was the level and amount of nursing care they had received.

We would have liked to have seen more awareness from the nursing staff of the aftercare programmes currently available. We would like to know how these are and could be

promoted to patients as well as what percentage of patients who access them. This information could be provided as part of a discharge pack.

If Barts is going to improve its patient experience survey results it needs to ensure it has specialist nurses and retains the critical role of the Cancer Nurse Specialists. It would be important, too, to check how last year's survey results had been used to improve services.

It seems that the current patient mix on the wards is difficult to manage and is difficult for patients with people who are dying lying in bed next to someone who is having fertility surgery.

There also continues to be a 'silo' approach to care without any evidence of a smooth transition between areas of care and equally once patients leave hospital. It was also concerning that the staff were not aware of services that patients could receive once they finished their medical treatment.

There is a sense from patients and certainly from staff that it would be preferable to have one specialist cancer service across Barts which would enable the development of specialist cancer nurses and other staff and provide patients with more of a one stop service. It would be interesting to survey patients regarding their preference as it may be the case that local communities wish to retain local services but patients would prefer to have specialist services further away.

Recommendations

1. The Cancer Nurse Specialists are highly regarded by patients and are key to the co-ordination of their care. We would certainly recommend that these posts are retained at current levels.
2. Reducing the staff ratio to one nurse to seven patients will almost certainly have a negative impact on patient safety on the ward as some patients have already expressed that they are worried about the care particularly at night. We would recommend that the staff ratio be maintained at one nurse to five patients.
3. Patients be consulted on the options of more specialist cancer services being provided on a single Barts site or services provided as part of general care service in their nearest hospital.
4. Better co-ordination of inpatient and aftercare programmes and an awareness programme on the wards of what other services were available post hospital treatment.
5. Some explanation be provided to patients regarding the current state of the old building and particularly the tunnel that was used to take them up to surgery.

Appendix 4

Ambrose King Centre Enter and View Report

Date / Time: Monday 23rd September 2013 / 10.00am -12.30pm

Healthwatch Tower Hamlets Staff:Shamsur Choudhury and Lindsey Williams

Contact at Ambrose King Centre: Dr LiatSarner (Clinical Lead for Sexual Health)

Address: Ambrose King Centre, Royal London Hospital, Whitechapel E1 1BB

Purpose of Visit:

1. To ascertain feedback from users of the Ambrose King Centre on their experience of using the service.
2. To find out if users had any suggestions for improving the services provided at the Ambrose King Centre.

Key Facts/figures about the Ambrose King Centre

- There were 35,000 visits in the year 12-13.
- 40% of users are under 25 and 20% of users are men that have sex with other men (MSM).
- 50% of users are from Tower Hamlets.
- 48% of users are white; 21% black and 15% Asian.
- 13% patients diagnosed with STI (16% M; 10.5% F)-mainly heterosexual <25 and MSM >25
- Most users access the service by friend's recommendation or via searching online.
- There are plans to move into new premises in the near future.

Please refer to attached '**Appendix**' for service information (Page 7).

General Information (Information gathered from discussion with management and general observation)

- There is good signage for directing people to the Centre from Whitechapel Road (front of Royal London Hospital); however the signage is poor from the back of the hospital i.e. from Stepney Way and roads behind Stepney way. One particular sign at Newark Street directed people the wrong way as this sign leads to a road that has been blocked off due to work being undertaken at the new hospital.
- The information Board (i.e. contains information on service and opening hours) outside the main entrance of the centre is not easily visible to users due to the positioning of the notice board (stuck on the wall on the right side) also information inside the notice board is written in very small fonts- it's not obvious to everyone that it is a information board.
- Currently there are no patient involvement activities and they do not have a patient group. However they acquire patient feedback via the NELNET Survey and Mystery shopping. There are also plans to collect patient feedback via a 'Comments Card' and they are now in the process of rewriting the 'generic questions' on the Barts Health Comments Card to make the questions more suitable for sexual health services.
- Leaflet racks were half empty in both male and female waiting areas.
- The layout of the Centre is not user friendly for individuals with a physical disability.

- There are plans to install Wi-Fi in the near future.
- TV Screens in the waiting room was not switched on (not sure if they work).
- Having separate waiting areas for male and female is a good idea- it makes users feel more comfortable.

Patient Comments/Feedback

The Ambrose King Centre has separate male and female waiting areas. The comments from the female waiting area were collected by a female member of staff and the comments from the male waiting area were collected by a male member of staff.

Female Waiting Area Comments

Patient 1

I've visited this clinic a couple of times now, I find the walk-in service easy to access and I am usually seen on time. I find the staff friendly and informative. Overall I think the service is good.

Female; 20's; White British

Patient 2

I've been coming to this clinic for a while now; I think the service is okay. I tend to use the walk-in service; the walk-in service normally has a waiting time of up to two hours (which is the expected time for most clinics, so I don't mind). I've noticed that the walk-in service is busier in the morning then it is in the afternoon. As for the location, I think if I was a new user to the service I might have difficulties finding the premises.

Female; 20-30s; Caribbean

Patient 3

I've been coming to this clinic for years now and I think the staff and doctors are very approachable and welcoming.

Female; 30s; Other

Patient 4

I think the online service is really good and I also find that the location is quite discrete which is a good thing too. The nursing and clinical staff are friendly, but I find the receptionists can be unwelcoming at times (in the way that they talk to you), which is a bit of a letdown.

Female, 20s, White British

Patient 5

I've booked my appointment online and I have been waiting here for nearly 50 minutes, which I think is too long. I think that if I accessed the walk-in service than I should be expected to wait for that amount of time but if I've booked online, than I should be seen quicker than that, apart from that the staff are nice and I like the location.

Female 20s other

Patient 6

I came in today to book my appointment and was told to come back from 9.30am, the time now is 10.30am, it's been nearly an hour and I've still not been seen, which I think is a bit long. Apart from that, the staff and doctors are polite and friendly, but the receptionists can sometimes come across as rude in the way they respond when dealing with enquires.

Female; 30s; White British

Patient 7

I've been coming here for four years and have no complaints with the service that's been provided. Last time I was here, my mother came with me who could not speak English but was provided with an interpreter, which was really good. I also think the staff and doctors are really nice and are easy to talk to.

Female; 30s; White European

Patient 8

It's my first time here and I think the staff are friendly and polite. I think the location is fine but it's a bit difficult to find, I had to walk around the building twice before I found the entrance, I actually thought it was a building-site. So far the waiting time is ok and I think the environment is clean.

Female; 20s; White European

Male Waiting Area

Patient 9

The receptionist is very helpful; she gave me information about the services provided here. The nurse I saw was very good; they were attentative. Last time I came here I waited 1.30hrs to see a nurse, but I did not mind. Today I am here to speak to a nurse about my test results; although I could get my test result by SMS or email I opted to see a nurse to speak to them about my test result; I think them providing this option is very helpful- it's more reassuring. Today I waited 40 minutes and I am very happy with the service I received; the nurse was very reassuring. The waiting area is ok; could be better i.e. better lighting, also the seating area and reception area is very close, sometimes you can overhear other people talking; but I guess this does not matter so much as there are only other men here, so there is no need to feel embarrassed. There is also a female receptionist working here today; I don't mind her, but other people might.

Male; mid 20's; Hungary (lives outside the borough and friends recommended service)

Patient 10

This is my second time here, I think the location is accessible and easy to find. The website for the service is very good. Staff are very nice, they make you feel comfortable and the receptionist is also friendly. I booked an appointment yesterday via the website and was given an appointment for today, so far the appointment is running 40 minutes late; it would have been useful to know if you had to wait 40 minutes in advance. I feel as long as you get the treatment and service you came for, the environment of the clinic is secondary; it's better to spend the money on things that will help users. I also feel that having a separate waiting area for men and women is a good idea, everyone feels more comfortable to access the service.

Male; mid 20's, White British (lives outside the borough and heard about the service via word of mouth)

Patient 11

The wait for the drop-in clinic is quite long, you have to wait at least 2 hours- but I guess the wait is expected due to the nature of the service so I don't mind waiting. The frontline staff are very friendly and the clinical staff make you feel comfortable and are non judgemental. The waiting room is slightly warm, it would be great if they could turn down the heating a bit more, it can get uncomfortable especially if you have to sit here for a few hours. Also they could do with a few more leaflets, as the leaflet racks seem pretty empty. I like the fact they communicate with people using different methods i.e. you can get your test result via SMS.

Male, mid 20's, White British (Resident of Tower Hamlets)

Patient 12

I was referred here from St Barts; I got an appointment here very quickly and was seen quickly. Staff here are excellent and everyone here is very helpful. I was very happy with the consultation with the clinician; they explained things properly and made me feel comfortable. I also feel the directional signs for the AKC from the main road are very good; I did not experience any difficulties in finding the centre. I really don't have any suggestions for improving the service so far I feel everything is ok here.

Males; 30's, White British (lives outside the borough)

Patient 13

It's my first time here, I came here at 10.20 and was told I might be seen by 11am, and now it's 11.40am- so the wait is quite frustrating. The receptionist has been helpful so far and signs leading from the old Royal London Hospital are quite good, I did not have any problems finding the Centre. The opening times for the centre could be extended to make it more convenient for people who work; they should open at 8am and close at 8pm. The opening times of the AKC is the main reason why I usually don't come here, I usually go to the Dean Street Clinic because it opens at 8am.

Male, mid 20's, White British (Resident of Tower Hamlets)

Patient 14

I live in Leyton and Googled sexual health services and this place came top of the list on Google. I went on their website and booked an appointment and got one for today. I got a confirmation of my appointment via SMS and in the SMS it highlighted that I might have to wait 45minutes before I am seen- my experience of booking the appointment via the website was very good. So far the staff I have seen have been very helpful, however I did find it difficult to find the Centre; it just does not have a proper entrance. My suggestions for improving the service would be to reduce waiting times and open late in the evenings.

Male; mid 20's, White British (lives outside the borough)

Summary of Patient Feedback (Common Themes)

- Majority of the users gave very positive feedback about the clinical staff; they said clinical staff made them feel comfortable and are non judgemental.
- Users feel the website for the service is easy to find as it is ranked high in Google.
- There are positive experiences of using the online booking system.

- Users like the different methods available of getting test results i.e. SMS
- Directional signs from main road are deemed ok from the perspective of users that have used the service before, but new users could potentially experience difficulties in finding the Centre, mainly due to the discrete location and building works surrounding the Centre.
- There are suggestions for extending the walk-in service opening times (before 8.30am and after 6.30pm) as current opening times is not deemed suitable for people who work.
- Waiting times for the walk in service seems to be an issue for users; most users stating that it can usually takes almost 2 hours before seen by clinical staff.
- Some users (female waiting area) thought the receptionist is not welcoming; these comments did not resonate in the male waiting area; in fact the most of the male users said the receptionist is friendly.
- There is confusion amongst users about appointments that are booked via online and text, users seem to be assuming that they are given a fixed appointment time - hence numbers of users have commented that their appointments always run late. However AKC management have confirmed that everyone that is asked to attend a walk in service is 'not' offered an appointment they are offered a 'appointment slot' e.g. asked to come in at a specified time (appointment slot) and they also said that they always remind users that the appointment time given is not the time they will be seen- people are generally required to wait at least 40-45 minutes and sometimes even longer depending on number of users attending the walk in service on that day- the information about potential waiting times is highlighted to users via SMS or their preferred method of communication.

Recommendations /Suggestion for Management

- There needs to be more pro active approach to getting users involved with service feedback; delivery and design. We would strongly recommend the AKC looks at developing a user group specifically for sexual health services. This user group could be virtual or meeting based and interest in joining the group could be promoted via the 'Assessment and Triage' form and the website. In the longer run our aspiration would be that the AKC proactively engages and involves users of the service in all its future plans and decision making.
- As majority of users of the service are in their mid 20-30's, AKC management should consider using different mediums to communicate with users i.e. they could use social networking sites like Facebook or Twitter to let users know if the walk-in service is running late or provide updates about services generally.
- Review and update the direction signs from Stepney Way and surrounding roads and put up better signs on the roads behind the new Royal London Hospital.
- Make sure that there is monitoring of the leaflet racks to ensure that leaflets racks are always full.
- In order to tackle the confusion around booked appointment times and appointment slots; it would be useful if the receptionist reminds the user when they attend on the day that this is not an time specific appointment and they might have to possibly wait up to 45 minutes to 2 hours until they are seen.

Healthwatch Tower Hamlets representatives and staff would like to thank Dr LiatSarner and her team for making all the necessary arrangements in organising the visit and for helping us during our visit.

DISCLAIMER:

1. The observations made in this report relate only to the visit carried out at the Ambrose King Centre on the 23rd September 2013, which lasted for 2.5 Hours.

2. This report is not representative of all patients/service users/carers. It only represents the views of those who were able to contribute within the restricted time available.

Appendix- Supplementary Information on the service (supplied by Dr LiatSarner)

Ambrose King Centre - What is the need?

- Tower Hamlets 5th highest rates of STI in England disproportionately affecting young people, MSM and BME.
- High prevalence HIV (6/1000) with 25% undiagnosed and 16% diagnosed late
- Teenage pregnancy rates higher than England average, although reduced by 45% since 1998
- Young population
- Increasing population of MSM in borough

Ambrose King Centre- What They offer:

- Open Access - No referral necessary
- Confidential and non-judgmental (You're welcome accredited)
- Full range of sexual health testing available
- Immediate diagnosis with onsite testing and results
- Immediate free treatment
- Full range of contraception
- Specialist services for sexual problems, sex workers, complex genital issues including ED/genital dermatology/difficult warts, complex contraception
- Partner notification and results management
- Clinical psychology and counseling services for high risk sex and sexual problems

Ambrose King Centre- Staffing:

- Consultant led service
- Specialty and primary care trainee doctors
- Nurse practitioners
- Junior nursing team
- Sexual health technicians
- Health advisors
- Clinical Psychology
- Reception and support staff

Ambrose King Centre- How do patients access?

- Website: www.bartssexualhealth.nhs.uk

Walk in: Monday 8.30-6.30; Tues/Thur/Fri 8.30-4, Wednesday 11.30-4

Text: Monday-Saturday including Monday and Tuesday evenings

Book online: Monday-Saturday including Monday and Tuesday evenings

Patient Journey:

- Reception
 - Patient completes registration and triage form
 - Receptionist checks form for accuracy and assesses whether patient needs to be seen urgently
 - Reception informs patient of their slot time if walked in, or signposts to waiting room if being seen straight away (urgent, booked by text/online)
 -

Appointment based services

- Clinical Psychology
- Sexual problems services
- CV clinic
- Health Advisors
- Complex male and female problems
- Contraception including coils and implant insertion/removal
- Sex worker clinic
- Genital dermatoses
- Anoscopy

Patient Feedback NELNET Survey 2012

- Good
 - 97% trust and confidence in staff
 - 94% Recommend to others
 - 96% Satisfied with care and treatment received
 - 97% treated with dignity and respect
 - 93% rate care as good/excellent
- Not so good
 - 82% reception staff welcoming
 - 88% reception clean and welcoming

Patient Feedback

- What do patients say?
 - Waiting times & Access
 - Environment
 - Staff
- What have we done in response?
 - More evening clinics, expanded Saturday
 - Increased ways of accessing and reduced waiting times
 - Refurbishment of waiting areas and female reception
 - Electronic patient record reduced reception workload & waiting times for patients
 - Customer services training for reception staff

Patient Comments

- Everything excellent. I had no problems
- The only thing I was unhappy with was the wait
- Everyone I dealt with was absolutely lovely
- Online booking is very convenient and efficient. Liked getting a text confirmation
- Make the waiting area less quiet
- Always been an excellent service