



Gynaecology Service Royal London Hospital

A report on patient experience.

November 2019

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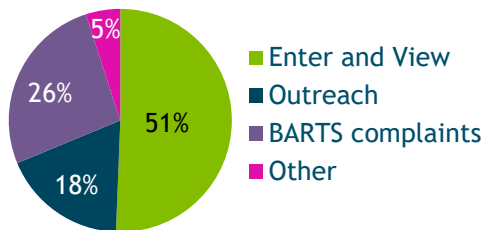
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Introduction

During 2019 Healthwatch Tower Hamlets heard from 72 gynaecology patients at the Royal London Hospital, identifying 382 comments. Nearly half of these comments were obtained during a series of Enter and View visits¹ by staff and volunteers in autumn 2019. We visited:

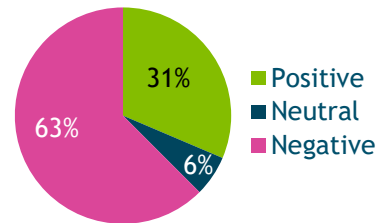
- Gynaecology Outpatients
- Emergency Gynaecology Unit (EGU)
- Gynaecology Inpatient Ward (8C)

The patients we spoke to during our visit to Ward 8C included non-gynaecology patients.

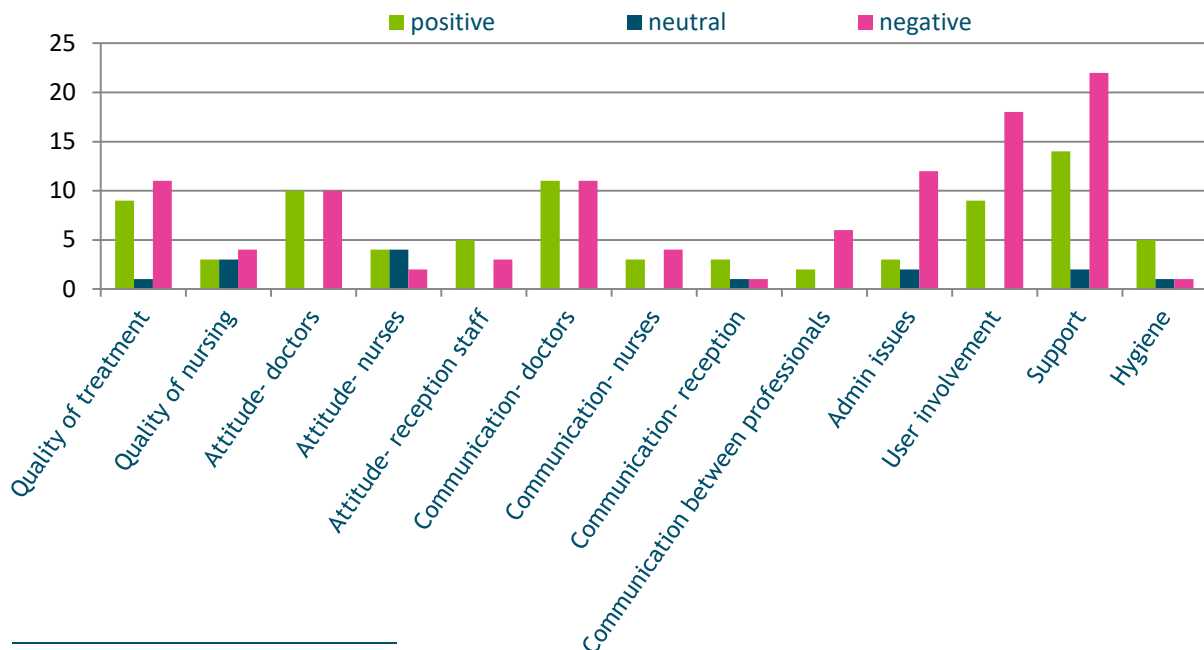


Summary of patient experience

Overall, patient opinion of gynaecological services at the Royal London hospital are leaning negative



Patients are positive about the environment; praising the cleanliness of wards and other spaces. The quality of the food is generally perceived as good and many patients are complimentary about the staff. However, patients also criticise multiple aspects: some patients feel unsupported and insufficiently involved in their own care, admin issues negatively impact patient experience and communication between medical professionals is sometimes poor. Opinion on the quality of care, the attitude of staff members and communication between patients and staff vary widely, with some having more positive opinions than others.



¹ Healthwatch Tower Hamlets has a statutory right to 'Enter & View' certain premises to talk to users and observe activities. The purpose of these visits is to hear and see how people experience the service and collect the views of services users. The results of these visits are

reported to providers, regulators, Local Authority and NHS commissioners and quality assurers, the public, and Healthwatch England, and are used to develop insights and recommendations to inform strategic decision making at local and national levels.

Our findings

Patient Insights

There is broadly positive feedback about environment in outpatient waiting rooms and on the ward, including hygiene and food; although opinions on stimulation were mixed and a few patients reported not having food options adequate for their specific needs or receiving the wrong food consistently.

Generally, patients with straightforward conditions received a good level of explanation about their condition from doctors, while more complex cases necessitating multidisciplinary care were more likely to encounter communication problems. Many found communication between medical professionals (consultants in various departments, GPs, nurses, bed managers) to be poor, resulting in a poorer quality of care and causing patients needless stress.

Patients perceive the inpatient ward as being understaffed, with nurses and catering staff struggling to respond promptly to patient needs. This can contribute to a general impression of poor organisation/ poor communication from the patients' point of view.

Experiences around quality of care vary; in particular, a few cancer patients felt unsupported and questioned the treatment they were receiving.

Some patients said they did not feel safe or well cared for. This appeared more pronounced for non gynae patients who were being cared for on Ward 8C as no beds were available in the appropriate wards. These patients seemed more confused about their care and who to communicate with in order to have concerns answered. This was creating a general sense of anxiety on the ward.

● *[I was taken to the trauma ward where I had a good experience] However, that*

safe feeling left when I got moved from that ward to this ward. I was barely told; in fact, I don't think my doctors were because they told me after they didn't know where I was. In the Royal London they have something called the 'disappearing patients' because the bed managers keep moving people at random times, the doctors they've gone - so sneaky. So I decided to go on a hunger and medication strike, since I wanted to speak to the bed manager - they need to know that I didn't feel safe. I was being moved around like some object with no say or information beforehand. I want to be focusing on my health not starting a campaign but no -one listens here. I feel like there's a miscommunication even between the patients and staff - the doctor came and told me that I was making things worse for myself as though this is something I wanted to do. I could tell she came with her privileged self not understanding the position I was in. In the trauma ward I was getting physio and progressing but here I barely feel safe to do so. I had to teach one of the staff how to move me correctly- it wasn't her fault she didn't know how to deal with an ortho patient like myself. It's that whole 'lodging' thing that they do moving patient to places they are not specialised for. Bed managers - they need to be taught to go about their jobs another way because they sneak in and out creating issues without talking to staff or nurses.

(Enter and View, Ward 8C)

The hospital tries to ensure women are able to see a female doctor if that is their preference; however, this is not always straightforward and patients who prefer female gynaecologists may wait longer or encounter communication issues.

Outpatients and emergency patients report waiting for a long time to see medical

professionals, in some cases with poor communication around waiting times.

Ward Layout

There are real concerns with EGU and Ward 8C in terms of patient flow. From what we were able to understand the recovery and consultation rooms for EGU are being used by outliers/overspill from other parts of the hospital that have a bed shortage. This used to be a winter problem but is now happening almost permanently.

The impact on EGU is that they are unable to take patients to a separate counselling room following their treatment/bereavement; instead this has to take place in the ultrasound room. This significantly slows down the ultrasound process and was the main contributing factor to the long delays we observed on our visit.

Only one toilet is available for both EGU patients and people in the waiting area. All patients need to empty their bladder before the ultrasound and if somebody else is in the toilet then the whole ultrasound process can take longer and patients start backing up.

EGU had been unable to use their recovery room for over a week prior to our visit. This can mean that they are unable to carry out medical miscarriages, as the recovery room is full with outliers, and they have to send women away to come back the next day. That can understandably be upsetting for patients.

The recovery room, which is doubling as an extra room for Ward 8C, has a toilet but no shower. Sometimes women can be there for several days and it does not have the facilities of a proper bay. It can also seem quite isolated as it is separate from the main ward.

Staff

The nursing staff on Ward 8C have applied for a gynaecology nursing position but are finding that they are caring for a large number of non-gynae patients for which they may not have the up to date skills. This is understandably frustrating for both staff and patients. Patients with non gynae conditions are not being nursed by appropriately skilled staff.

Recommendations

1. Improve the administration processes both with patients and between professionals and departments. This is particularly important for patients who may have multiple conditions or may have an unclear diagnosis.
2. Make sure that it is clear to patients who they can ask for information about their diagnosis, condition and planned treatment. Signposting to a trusted NHS approved website that provided more patient focused information and explanations of medical diagnosis and conditions would enable patients to better understand their conditions and be better patients.
3. Make sure that patients are clear who their consultant is and who's care they are under.
4. Change the policy of using the EGU recovery and consultation rooms for Ward 8C outlier beds or move EGU to where they have dedicated recovery and consultation rooms.
5. Could an outliers ward be opened at the hospital as a solution to semi-permanent bed pressure with more generalist nurses.
6. If outliers are going to be regular fixture on 8C then:
 - there needs to be appropriately trained staff for the type of

- patients on the ward. Could they be grouped better around particular specialisms.
- the recovery room needs to be turned into a proper bay with a shower.
 - EGU need a dedicated toilet, recovery and counselling room.
7. Avoid moving patients at night.
 8. If patients are being moved at night limit the amount of noise and disruption that causes to other patients.
 9. Effort to make the ward a quieter place would be appreciated by many patients. Could there be a sign up about considerate phone use?
 10. Ensure that care is based on what matters to the patient and not what's the matter with them. What is worrying them the most?
 11. Ensure that patients understand the food choices available to them and that they are receiving the food that they have chosen.
 12. Could the Barts Charity or the Friends of the Royal London hospital focus a project on improving stimulation for patients on wards. Could a Royal London Hospital App be developed that gives patients information on how wards function as well as link to games, TV/Film download services (Idea Store link) with a guide on how to use it. Perhaps volunteers could be on hand to show less digitally confident patients how to use it. Could the food menus also be available on the App so patients had more time to view the options.
 13. Improve the waiting times for EGU patients waiting to be seen on the day.
 14. If waiting times do increase, explain to patients why and how long they are.

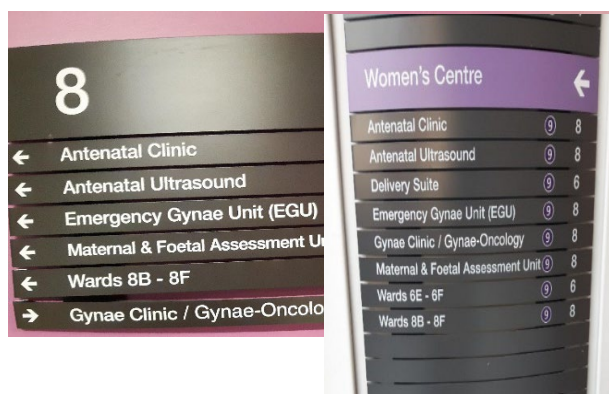
15. Provide access to better information, or trusted sources of information, to enable outpatients to better understand their diagnosis and conditions.

From a community perspective, it feels that the management and staff are doing their best in an increasingly pressured environment. We know our local population has continued to grow rapidly and is getting older. We don't feel that our local hospital is receiving the additional funding to meet these increasing demands and this is starting to manifest itself in an inability to maintain or improve the quality of care. As residents we would like to support Barts Health Trust to seek further funding from the government to adequately resource our hospital to meet the needs of our community.

Emergency Gynaecology Unit (EGU)

Getting there

Signage to the gynaecology services was relatively easy to follow'



The lifts were very busy and once one or two people with a buggy or wheel chair entered it quickly backed up so we had to wait for several lifts. We finally noticed a poster saying that you could use lift core 1 instead of 9 which we ended up doing and it was much faster.

When we arrived the waiting area was calm and cleaning was in progress.

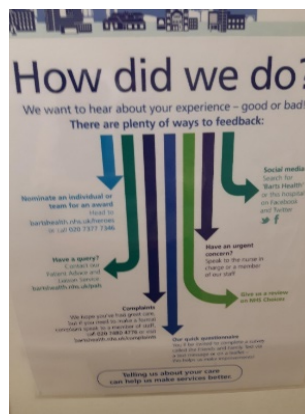
We found the reception area but there was nothing on the desk or on the wall indicating it was the reception for EGU.

While we were sitting in the waiting area two people came to the reception and needed to be given directions somewhere else. We imagine that could be frustrating for the receptionist. Better signage, a map, or clearer directions on people's appointment letters could probably solve the problem.

The sign that came down from the ceiling had tape and hand written in pen EGU, Ward 8C. People may not know what EGU is

unless this is clearly stated on their appointment letter.

There was information on the walls about PALS, We Care, FFT and a poster re tell us what you think about our services. But there was nothing on the You Said, We Did board.



There was a sign which said children were not allowed on the ward but a couple with a six-month baby were in the waiting room for a long period. This may be distressing for women or couples who are in the middle of experiencing a miscarriage. We appreciate that other women may not know or be able to organise childcare. If it was explained to parents before they came we're sure that they would understand.

Information was up on the walls re domestic violence and the miscarriage helpline. Sands bereavement support app cards were available at the reception desk also.

Chairs were available at different heights which was good - not sure that people know that though.

The fire alarm went off while we were there but there was no mention of it being a test by the receptionist and we didn't see a sign up. There was a sign down stairs at the main entrance however.

Observations

The clinic started to run very late. The receptionist did announce that the clinic was running late when it got to about an hour and half. He apologised for the wait when it got to about two hours.

One patient started to get agitated and said very loudly *“I am so annoyed I want to just leave, but that would make the last two hours I’ve waited a waste of my time.”*

Overheard one staff member telling a patient that it had taken them a while to get the image or letter for them because they were waiting for the computer to reboot.

Layout

There are real concerns with EGU and Ward 8C in terms of layout and shared space. From what we were able to understand the recovery and consultation rooms for EGU are being used by outliers/overspill from other parts of the hospital as there are not enough beds on the appropriate wards. They are forming part of Ward 8C. This used to be a winter problem but now is happening almost constantly.

For EGU this means that patients, who may have just received upsetting news, are not able to be taken to a separate room to have a conversation and counselling re their treatment/bereavement. This has to take place in the same room as the ultrasound. This significantly slows down the ultrasound process and was a contributing factor to the long delays we observed. It may also mean that staff rush conversations as they are aware of the growing back log.

Only one toilet is available for both patients and visitors in the waiting area and ward. All patients need to empty their bladder before the ultrasound so if somebody else is in the toilet then the whole ultrasound process can take longer and patients start backing up.

They had also not had use of their recovery room in over a week. This can mean that they are unable to carry out medical miscarriages as the recovery room is full with outliers therefore they have to send women away and ask them to come back the next day. That can understandably be upsetting for patients.

Patient Experience

Patient 1

“GP referred me, I went to the GP because I had pain on right side of my belly so the GP tested my urine and found out I was pregnant, then about 4.30, the GP called EGU and they said I have to come here today. GP wrote a letter, I just needed to show them at reception. Basically because the GP found out I’m pregnant - they think it’s maybe urine infection or not. I’m bit worried and it’s my first time as well.

After waiting two hours, I mostly think they need to improve timing people waiting so long I got so bored and frustrated. Don’t know when they going to see me, my husband has left now because he need to go work or else he going be late for work.

After finishing my appointment: -They are quite good, the staff are really nice. They took my blood they said I have to wait for blood test, otherwise everything fine. They need to improve the waiting time it’s not good they kept people waiting 2 or 3 hours. They also need to improve reception service”.

Patient 2

“We phoned 111 last night. Went through the questions. Only took 5 -10 minutes. They said we should go to Out of Hours and they put us through to OOHs and they said there was an appointment 11:45 pm (in 20 minutes) if we could make it there. They booked the appointment for us. We got there and were seen pretty close to that time. They said that we would have to come here (EGU) in the morning and they

phoned here we think and left our number. We got a call at 8:45 this morning to say we could come in this morning. That all seemed to be a very impressive service.

The only thing that went wrong was that when we got here this morning they said that we needed a referral letter from the GP (OOHs). We went down to the Out of Hours but it was closed. Luckily the Urgent Treatment Centre is in the same place so we asked them there. They thought it could be a problem but luckily they could. We got the referral letter and came back up here. There seemed to be a good connection between 111, Out of Hours and the Urgent Care Centre.”

Patient 3

“Have been waiting for over an hour. The car is going to run out on the metre and my partners going to have to go and drive around for a bit. I’m worried he’s not going to be here for the appointment.

I had a GP appointment booked to register a pregnancy but I had a miscarriage. I called the GP yesterday (Mission Practice) and they called back. They made the appointment here today. It’s a horrible appointment and I don’t like hospitals. I’ve asked how long they think it might be but they don’t know. Other people seem to be going in before me.

It had been going smoothly until this point. I’d had phone calls with the GP. We had a holiday booked to Barbados but they advised that we don’t go because of the Zika virus.

I phoned again when I thought there were issues. They said I wasn’t far enough along and I’d have to wait before they could check.

The phone service at the Mission is good if you just want some advice. I work full time and the phone consultation is much more convenient. You don’t want to clog up the GP appointments - want to leave them for people who need them.

They’re going to check if everything is gone.”

Patient 4

“My GP referred me here but don’t know why. I have a stomach ache. I only know they will scan me; I don’t know how far pregnant I am. Two weeks before I came they said my baby was too small but I’m not bleeding. I had the same symptoms before, I feel angry and I’m stressed. This is my second baby; my other child is 4 years old. I have been waiting for 45 min. None of my sisters have experienced anything like this. The nurses always give negative feedback. I wish someone could explain in more details. Wish they would give me more information about my condition. I can speak English fluently so there’s no need to have an interpreter. And no one asked me how I am.”

Recommendations

1. Improve the signage at the reception desk and wayfinding information on patient letters.
2. If you ask patients for feedback on services, please display information on what impact it has had.
3. Make it clear on appointment letters, if it’s not already, that children are not allowed in the waiting area and explain why.
4. Improve the waiting times for people waiting to be seen on the day.
5. Change the policy of using the EGU recovery and consultation rooms for Ward 8C outlier beds or move EGU to where they have dedicated recovery and consultation rooms.

Ward 8C

Environment

It was unclear in the ward as to which patients were actually gynaecology patients as there were several patients who had been placed there, we later discovered, because there were no beds available in the ward most appropriate to their condition.

Observations

Random bottle and cup on patient table that she didn't recognise, it did not belong to her. The call bell was on a hook far away from patient that would make it difficult for her to reach it.

Comment from staff member

One staff member said *"I think the ward is good in that if you need help you have people that you can speak to and ask questions to. We have our daily handover which is informative - if there's any issue it's like a chance to speak up."*

There are times when you do feel overstretched on this ward, there are 20 beds and two HCAs but then they open up the other bay and make it 24. At that point, the ideal situation is to have three HCAs but that doesn't always happen."

Another staff member indicated that they would like to look for another job *"I wanted to nurse here and I wanted to work in gynecology but it is so busy. Sometimes my lunch break doesn't happen until 4pm. Sometimes I don't think I'm able to do a good job of caring"*

Patient Experience

Patient 1

"I have been in for two days. I had surgery back in August to have a big apron removed. It was carried out at RLH by plastics. There was no duty of care what so

ever, I was discharged after 5 days and my follow up is in December.

Following the operation fluid starting building up and I started splitting open. I went to Queen's but they didn't treat the wound, so I went to my GP they couldn't do anything either, so I went to A&E. I waited 11 hours. They recut me open and put a vacuum in and drained out all the fluid and infection. I felt like a million dollars afterwards.

I still had two drains attached, one of them was stitched into place. I always dread going into A&E, they find it difficult to get drains and drips in, or find a vein for that matter. Post-surgery after care is ridiculous. No contact what so ever. General surgeons can't do anything. I was put in ambulatory care. Plastics on 3D was really good. I was there when my wound became infected because of the fluid build-up. They used glue to stitch up the wound initially and it didn't hold, after the wound opened and became infected and they re-did the surgery they used stitches and it healed better. When they did the first surgery they didn't consult me at all. My surgeon passed away, so I had someone different, who came in and said I'm going to do this, this and this. He did as he pleased and not what was agreed with my original surgeon who was a very positive surgeon.

When they discharged me I wasn't under the care of district or community nursing. I didn't meet the criteria. So when the fluid started building I went to my GP practice and saw the nurse who kept changing the dressing and the GP did have a look.

I came back to A&E because the fluid was building a lot. I also had bariatric surgery in 2014 at the Homerton. They didn't pick up that I had a hernia. They also cancelled appointments frequently. I didn't see a dietician; I didn't see a post-surgery nurse all were cancelled.

No one listens to me in hospital.

In terms of respect and dignity it could be better, I've heard things whilst I have been here on this ward, things I don't want to hear, very sad decisions being made.

I don't feel I can raise concerns. If you go against the grain they take it personally. Following the removal of my apron, they didn't give me a belly button. But I felt that I couldn't say anything.

I have type two diabetes, but I am not a pin cushion. I don't need my sugars checked constantly, and they come at the most inappropriate time like when you're about to fall asleep. If you say no they give you lectures and attitude. Their attitude is terrible. I would happily sign to say I refused for my sugars to be tested.

I saw the surgeon today, but she was in a rush. She was here for two seconds, and said I needed a scan. I don't know when this scan will be, today, tomorrow, I don't know. No eye contact, I felt deflated, I couldn't even ask a question. But in comparison to Queen's hospital I get more information here at RLH. At least at RLH they do tell you somethings.

People who deliver the food are lovely, and I like the food. The food is nice. Staff have tried to make me feel comfortable, they have offered me a reclining chair. But there is no tea or coffee. Not even a machine. Overall, I don't feel staff are sensitive to me needs. Most of them act like they are listening when they're not."

Patient 2

She had been in hospital since 1st of October (now 30th Oct), she came in at 5:30 pm since she had been vomiting from 10 am. She has had a stoma and they suspected that their might be a blockage. She has had a colonostomy and has no bowel movement. A bed was not found for her until the 2nd Oct.

She came to A&E at Whipps Cross via car. It took her 20 hours to find a bed, she spent 8 of those hours sitting in a chair in A&E

until the daughter insisted that they find her a stretcher. She was then on a stretcher in the corridor in A&E. They then found a bay to put her in and put in an NG line in. She was then put her back in the corridor again and was given paracetamol, but no drink. Insisted on an IV that was given at midnight.

On 23rd Sept, her GP had referred her to the Gynae department at Whipps Cross to receive a scan, it was on the 2nd when she was in the hospital that they completed that scan with an additional CT scan. She said that the surgeon came in and suspected that she had a gynae problem. This was followed by a MRI scan on the 4th of Oct, it was then that the general surgeon had informed her that there was a mass on her ovary.

She was prescribed Gastrografin, a medication with the side effects of sending your bowel into spasms, along with vomiting. She hadn't had any food since the 1st Oct and she started vomiting fluid and bile.

By the 5th October, she began to feel better, they connected an NG tube to her and she actually ate a quarter of a potato twice during the day and had a little bit of soup. However, she began the next evening. By the 7th, her abdomen began to swell up as it was full of fluid, they drained 3 litres of fluid from her.

The treatment at Whipps Cross felt like it was from unqualified staff. It was like they'd never seen a university. Poor quality care, poor safety and no precautions. When we tried to help we were told not to touch anything and that we were breaching safety. She went 20 hours without anyone replenishing the IV. We complained to the surgeons. Nobody listened.

On the 8th October, the Respiratory Doctor and HDU team came to assess. She began wearing oxygen mask for a bit.

The following day there was an MDT meeting and a Gynae doctor came to see her and had said the fluid contained malignant cells and they were going to transfer her to the Royal London, the bowel obstruction would be dealt with there as well. The picc line was done on 9th Oct in the afternoon. 10th Oct started TPN 1 o'clock in the afternoon.

Nurses at Whipps Cross were a nightmare. Said hadn't got TPN on 9th Oct. Needed to be 2 nurses to start it.

Brought here in a chair in an ambulance on 10 Oct. Started TPN again about midnight and gave another lot of Gastrografin on 11th Oct which led her to begin vomiting again.

Saturday morning her temperature had spiked, so had an infection. Second spike occurred on the 12th October, she was started on antibiotics. And on Sunday she seemed better as there was no temperature increase.

Friday 11th Oct, Dr. B said he was going to do an exploratory operation. If they can remove the mass - do a hysterectomy - they will. That following Monday, on 14th Oct, surgeon and anaesthetist came to see her and said would operate they had come back with radiologist and agreed.

She then had another temperature hike - they said it was a hospital acquired infection. One antibiotic was resistant so they started another stronger one. So they couldn't do the surgery. In those 7 days she had a lung clot, pneumonia, influenza, partial lung collapse, pleural effusion, On anti-coagulation medication. There was fluid building in her stomach again, she looked like a balloon that was about to burst for 7 days.

On the 10th October they put a drain in and drained 3 litres of fluid. We asked for our doctor, they said they wouldn't call them out. If she's had all that fluid drained there's a chance she can go into shock. She saw the house surgeon, general surgeon

and the same gynae surgeon. When the previous tests were done on the 23rd Sept they missed a 4.8 cm ovarian mass. The results said there was no ovarian mass seen. She had reported post-menopausal bleeding.

Because she hadn't eaten, she needed a TPN Picc line, we pleaded with him to do that but he said he had to go and pick up his children. Nutritionist hadn't signed off. There was an admin issue over the weekend which meant that they hadn't placed an order.

Friday 18th Oct nurses started coming with gowns, they were worried about her having a urine infection - she was put into a side room. But the doctors said she was negative for an infection. On Sunday 20th October she was moved into here (4 bay room), it turned out she didn't have an infection. But she wasn't able to have the surgery.

Tuesday 22nd October had biopsy with local anesthetic - because of the lung clot. We waited for the results for the biopsy. The TPN was put in again. If she sips they need to aspirate using the NG tube. They then removed the picc line as they thought it had become infected. She then had a catheter put in at Whipps Cross. On Monday 14 October they had removed everything.

On the Wednesday which was the 16th the NG was put in but then it came out. But because they didn't tape it in properly so when she had coughed the line came out.

On the 22nd Oct, she received a third NG line because of how much she was vomiting, they saw it was so acidic. They said she would have to wait a week for the results of the biopsy. The doctor said she had cancer of the upper GI tract. So not gynae - not ovarian - he said that he would hand her care over to another Dr.

He came today, and told us it's not curable as it's in too many places. They wouldn't give her chemo as an inpatient and she will

need to go back into the community. He said she wouldn't be under his care. If she went home and was transferred to St Barts then maybe.

At Whipps Cross they had switched off her TPN 5 hours after it was started (48-hour bag) as she couldn't have it in the ambulance.

They started on TPN on the 22nd, but from the 14th to the 18th of Oct they did nothing. Saturday 19th she was drained again around 2 1/2 litres. We have no idea who her consultant is now. There's been nothing about the bowel obstruction every time they come in. They never did an endoscopy.

She was admitted 17th May, 15th Aug, 31st Aug. Every time they get the stoma to work they send me home again. She keeps getting turned away, passed along, nobody has time to look at her.

They keep looking at her as separate bits and they are just trying to solve their bit. Bumping from one specialism to another. Nobody has put a camera down her throat.

We haven't had any information on what the care in the community will be yet. It could take 3 weeks for a home TPN. Nutrition team need to start now. Everybody is waiting. But they know it's spreading.

Patient 3

I came in on Sunday after I fell and got pretty badly hurt, they brought me in by ambulance I live in NW1 but to be honest I can't remember if they even told me I was being brought to RLH. I was in so much pain that I was out of it when I got to the hospital. They brought to me to A+E, I was at the assessment unit. I think I was given pain meds because I was so disorientated that it's a bit of a blur. But I got to the ward on Monday. I remember the first ward moving me closer to the nursing station to watch me, as I said I was all out of sorts and saying stupid stuff so they had to keep

an eye on me.

But then I got moved to this ward, and honestly one thing that I would say that there wasn't enough of a stimulation for people. The doctors would come and see me and tell me about my diagnosis but then that's it until someone else comes to give me my food. I understand that there are patients much worse than I am, there isn't enough nurses on this ward I don't think or enough staff. But I don't want to worry anyone so I don't ask for anything but I wonder if they could spend a penny to get something for me to do; colour or read a book. I don't think there's anywhere for me to go or ask, so I guess I'll just have to stay here. Luckily my friends came yesterday and I managed to speak to them for a while before they had to go. Even if I got a book or magazine that would be enough I wouldn't be disturbing anyone.

Look, they give us these jugs to drink but this much water is ridiculous I'm not going to be able to finish it all.

Patient 4

I've pressed the call bell for my insulin but nothing so far. I had my lunch two hours ago and I'm meant to have my insulin with my lunch, but every time I call someone not only does it take them up to an hour to get here but they leave and don't come back.

The nurses barely come on to the bay to check on us, we hardly see their faces. The tea trolley doesn't arrive as it should according to the hospital food booklet. Whenever I order my food, it isn't what I ordered and there's no explanation as to why I receive something different.

I honestly think there needs to be more care involved on this ward, like I and I'm sure the women here can agree, we don't feel cared for, it's like we're a nuisance. I need my medication so either let me do it myself or give it to me at the right time.

I'm partially sighted and the light for this place makes it hard for me to see at times, but I only have a lamp and not the overhead like the others do. There's so many inconsistencies.

Patient 5

Had abdominal pain on the right side. I went to the GP and he made an ultra sound appointment. They found there was a mass. Within two weeks I was referred to Newham hospital. Sent for blood tests and CT scan at Newham. I live in West ham. Within two weeks of that I had an appointment with the gynaecology consultant. Then referred me to RLH for surgery. They explained everything clearly at each stage. They were suspicious of the mass. Had operation on 24th Oct. All done Sept-Oct has been fast.

Been on the ward six days. Pain management has been ok. Nurses come when needed. They have spoken to me about being discharged. They are putting together a plan for me so I can go home. How I'll manage is my main concern. I'm worrying about what might happen. My toilet is very low. I'm not sure how I'm going to get on and off. That is my worry (patient was crying when she was talking about how she was going to manage at home).

I can't eat at the moment; it makes me vomit. They brought me some soup today but I didn't want to eat it because it was too thick. I haven't seen the menu as I'm on fluids. I haven't had a bowel movement yet so they are keeping me on fluids. They are good about making sure I have water and cups of tea. [The catering person came and asked her if she wanted anything while she was talking to us. She said no. But we asked the catering person if they had any thinner soup she could have, she went and asked the nurse, who said she was on liquids and the catering person said there was a clearer soup she could have.]

The nurses and staff are good but they seem to be having to do more things at once now. Paper, patients and computers. People are more ill and more complicated. If I call them and they don't come at once I know it's because they are with another patient. I feel looked after both at night-time, during the day and at weekends.

It's improved - the system - it's working. I was fast tracked through the GP, Newham to surgery here.

A couple of days ago a woman came in late at night with her elderly mother who was being admitted. She was going up and down the ward at night in her high heels. When you're in pain that is really hard to cope with. Maybe they could have thick socks or slippers that people could put on in that case. Could an airline donate some? Every little noise increases your pain. A patient in the bed across from me talks a lot on her phone with the speaker on. The son of the patient next to her asked her to turn it down a bit but when he left she just turned it up again. I suggested that she use head phones but you don't want to get too stroppy with your fellow patients as you have to share your personal space with them. Maybe a sign or something could be put up. Could there be a quiet policy about mobile phones? It's important to have that connection with the outside world but need to be reasonable and respectful as when you're in pain every irritation is huge.

Patient 6

I am not happy. I had surgery in my stomach to take out tumor in my stomach. I had a variety of scans and blood tests and everyone said to me 'Good news, the tumor is very small, we can get it out'. [This was later diagnosed as bowel cancer and I underwent chemotherapy at St Barts Hospital. After some sessions of chemo, I was considered suitable for surgery].

The operation was to be performed here by gynaecology. But will be going back to Bart's for follow ups. I was sent here to

gynaecology for my surgery. I got here, they had no notes no files. The nurse said this to me very loudly and openly in the waiting area. I don't feel like I have been treated with dignity or respect. Why should the whole waiting room hear my business and the fact that you don't have the notes or files.

Everyone here, before my operation were happy and friendly. They would hug me and cuddle me and take the time to speak to me a little. Since the operation no-one cares anymore. I still have the tumor; I still have cancer.

Before the operation I had scans, ultrasounds and MRI's. But the operation was not successful. The tumor is connected to the pancreas. If they had taken it out I would've needed a poo bag and a wee bag for the rest of my life. They've left it in there. It's just sitting there stuck.

Risks of the operation were all explained to me by the surgeon, but he was not supportive. I feel I have not been supported at all. After my operation they kept me in hospital for one week. They sent me home in a lot of pain from the staples and needles. They just booted me out. Couldn't wait to get rid of me. There was a needle in my neck and the nurse just yanked it out. I was in agony.

They discharged me because they don't have beds, there were plenty of empty beds on the ward. A lady who was fully mobile, using the lifts, going up and down with her family stayed in hospital longer than me.

Following the surgery and after I was discharged the stitches busted open, and all I could see was a big hole. I was angry hospital didn't keep me in and I didn't know who to turn to and where to go. I haven't seen the surgeon since the operation. They all seem nice and friendly and talk to you like they care, but they don't. I had the operation at the end of September and I am still in pain. They

should've cared for me. I hate RLH. I haven't been listened to at all. I haven't screamed and told them off for cutting me open and then leaving it in there. The chemo was working; it was getting smaller. I didn't feel comfortable to raise concerns as they might have stopped my chemo. They couldn't wait to get rid of me. I am really upset about the care (they need a better machine), because everyone kept saying it's really small, but they couldn't even take it out. They give you so much hope only for it to be dashed away, knowing it's never going to come up. They don't even care about how you might be feeling having had your hopes dashed here at RLH.

The doctor's at Bart's listen to me, but not here. I am able to ask for chemo and they listen. Since the surgery the impact on my life was huge, I couldn't go out, I couldn't do gardening.

When I was on the ward the food was alright. I had enough choices, I started doing exercises and people joined in. The staff were okay as well.

The environment here in gynecology is good, it's clean and reception is nice. Nothing wrong with the building, and they have provided with transport for all my appointments, even this one.

I have come to see the surgeon today for them to check that the wound has healed properly then I can start my chemo again. They said to come in for 12.30, but now they are saying that the surgeon is in surgery and they don't know if he knows that I am coming to see him today. They also said the clinic doesn't start until 2.30pm. But there are SHR's in the clinic and see if they can get one of them to have a look, but I could be here all day.

Patient 7

I had an accident at home and an emergency call ambulance was called in, to be honest I can't remember because I drugged up since I was in so much pain. [I

was taken to the trauma ward where I had a good experience] However, that safe feeling left when I got moved from that ward to this ward. I was barely told; in fact, I don't think my doctors were because they told me after they didn't know where I was. In the Royal London they have something called the 'disappearing patients' because the bed managers keep moving people at random times, the doctors they've gone - so sneaky.

So I decided to go on a hunger and medication strike, since I wanted to speak to the bed manager - they need to know that I didn't feel safe. I was being moved around like some object with no say or information beforehand. I want to be focusing on my health not starting a campaign but no-one listens here.

I feel like there's a miscommunication even between the patients and staff - the doctor came and told me that I was making things worse for myself as though this is something I wanted to do. I could tell she came with her privileged self not understanding the position I was in.

In the trauma ward I was getting physio and progressing but here I barely feel safe to do so. I had to teach one of the staff how to move me correctly- it wasn't her fault she didn't know how to deal with an ortho patient like myself. It's that whole 'lodging' thing that they do moving patient to places they aren't specialised for. That's what I meant about being safe, I can't do much myself but those that are supposed to do things for me can't do it properly because I'm not in the right place.

Bed managers need to be taught to go about their jobs another way because they sneak in and out creating issues without talking to staff or nurses. The nurses are good I would like them to be valued more.

Patient 8

This is my third pregnancy, my previous two pregnancies I miscarried. I have been experiencing quite bad vomiting and I can't

keep food down, my chest has been hurting and I am dehydrated. I am about nine weeks pregnant. I came in last night. I called my GP about my symptoms, GP called the gynaecology ward and I came straight here. They ran some tests and I had an ultrasound scan. Everything is okay with the baby.

I have been kept in because I am dehydrated and I have been on a drip since I came in. I am feeling much better. I saw the doctor earlier and they have decided to keep me in tonight and I will most probably be discharged on the 31st of October.

I feel I am able to express my concerns and what I am worried about. They are listening to me and taking good care. My GP practice is Island Health. The food was too spicy for me. Because I am experiencing bad gastric the spicy food is making it worse and I can't eat it. But my family will be visiting later and they will bring me more food. But there should be more variety of food.

The doctor did give me medication for the bad gastric and that has really helped.

The ward is clean enough but the toilets are very dirty. It's disgusting. I am comfortable on this ward and they are looking after me well. They have answered all of my questions, my only real issue has been the food. I chose the food from the menu but it wasn't explained to me that it would be spicy and it made my gastric worse. Otherwise the care has been really good.

Findings and recommendations

Effort to make the ward quieter would be appreciated by many patients. Could there be a sign up about considerate phone use? If people are being moved in the middle of the night could extra care be given to soft shoes.

Limit the number of outliers on the ward. Could there be a specific area? If there are constant outliers now could another ward

be opened up for them or could they be grouped better around their specialisms. It seemed difficult for gynae nurses to be nursing orthopedic patients.

Are staff asking what matters to patients, rather than what's the matter with them. Seems that sometimes they are being passed from consultant to consultant rather than seeing them as a whole person. This can mean that they also get passed from ward to ward and they don't know who to ask about their care.

Some people don't feel safe on the ward. This can be because they're moved at short notice or at night and they don't think their consultant even knows where they are. Also because they are being nursed by staff who don't know how to care for people with their condition e.g. orthopedic patients being nursed by gynae nurses.

Going home can be very worrying for people who live alone and who are going home a different person to the one that went in. It's very important to address the things that worry them the most to relieve that stress e.g. how am I going to maintain my dignity while going to the toilet.

There are few complaints about the quality of the food but the food choices appear not to be being explained to people adequately and people are frequently receiving the wrong food.

Outpatients

Layout

The waiting area is pleasant and clean. The locations of the information boards are a bit strange as you can't see them. The seats are facing forward and the boards are out of sight or you have to strain your neck to see them. There is very little information on the Boards. It would've been good to see a you said we did Board with information on it.

Patient Experience

Patient 1

"I have a diagnosis of endometriosis.

I came into A&E in severe pain, they suspected it was appendicitis, but discovered that I had endometriosis. They referred me to gynaecology. My GP is St Andrew's but they are not the appropriate people to deal with this condition. I am in the right place.

After the referral was made by A&E I waited about three months for the first appointment. They have decided on surgery. I have been in severe amounts of pain and a lot of bleeding.

I have been in hospital three times as an inpatient. I go to A&E, they give me morphine after looking at the pain relief system, last time I stayed 6 days.

They have decided on surgery. I have had an MRI scan and I have received the results of the MRI scan, but I do not know what it means. I have received the clinical explanation of the MRI scan. I do not know it would be sent to me also, I thought the results were usually sent to the doctors.

I think my surgery requires a bowel surgeon as well because they suspected my bowel is connected to my womb. I have had the pre-assessment, but I do not know what type of surgery I am having. No-one has explained to me anything about my surgery. My case requires MDT to look at it.

I have been given a provisional date for my surgery of 12th December 2019, but I have called the surgical team to ask for an earlier date.

I am supposed to have a specialist nurse I can contact if I have any concerns. I have e-mailed the nurse here, but no-one got back to me. The nurses can sometimes be dismissive of my symptoms. Once when I came here I told them that I had been bleeding for 26 days. They just said 'it happens'.

Otherwise the consultant and nurses have been amazing here. I have had great care when I have seen them. When I have seen them they have been incredible.

Today they are sending me around lots of places to get bowel medication. No-one knows what's going on. The receptionist finally managed to arrange for someone to come and see me and sign the prescription. I was trying to tell him my concerns about the surgery, but he just said that he knew nothing about my case, but he could sign the prescription. I am not listened to at all. They don't understand my concerns or worries. I think the doctors are trying to do their best, but the communication is not very good between them at all.

The communication between staff and departments is poor. I have had the results of my MRI for more than 2 months but have not been able to decipher what it means. I have been calling the consultants secretary, but she has told me that my case needs to be discussed at the MDT, but she doesn't know when this will be. They think my bowel maybe attached to my womb, but I can't be certain as no-one has told me what the MRI scan says. I asked my GP to interpret the results for me but they said they don't understand it and that they are not endo specialists. I have been chasing vigorously to try and find out what these results mean, but no-one is listening or understanding how important it is to me. Knowing that I have the results in my hands but not knowing what it means is causing me huge amounts of anxiety. I don't feel like I have been involved in my care or had a say as I do not know what is happening.

The area in itself is clean and nice. I found it difficult to find clinic as the signs disappear. My preferred way of being contacted for feedback from the service would be e-mail."

Patient 2

"I have a menstrual disorder, and I have had it for many many years. My cycles are fine, but very heavy. I have been seeing my GP for 4/5 years regarding this matter. They did the referral 2 years ago. I waited about three months for my first appointment. I was presented with two options for my disorder, to have surgery or have a coil fitted. I opted for the coil. The doctor explained everything very thoroughly, and my husband came with me to this appointment so that we could understand everything properly.

I haven't had the coil fitted yet due to circumstances. They told me they couldn't do it themselves and I would have to ask my GP to do it. I went to see my GP to have it fitted, but I felt that she felt quite nervous about it, as she said she hasn't done many, but she also advised it is easier to do during my menses. So I had to wait for the following month, but my GP was away. The month after I went on Umrah and couldn't have it fitted and then the following month my GP was away again.

I have already re-arranged this appointment once as I felt that it would be a waste of time as I haven't had the coil fitted. I wanted to re-arrange again as I still don't have the coil fitted but was advised that if I re-arranged again they would actually discharge me and I would have to be re-referred, so I have decided to come in. It would be so much easier if they could fit the coil. I don't understand why they can't. I tried to get appointment at Queens' Gynecology as that would be my local hospital, but they had no appointments available. I got tired of waiting and opted to book it here at RLH.

When I came for my very first appointment here, the doctor was male and he said he needed to do a thorough examination. This made me feel very uncomfortable and I asked for a female. He became very angry and rude, his demeanor changed and this was quite clear, cancelled the appointment and said I would have to come back.

When I came back I saw a woman this time. She decided she wanted to lecture me about the cost to the NHS and how expensive it was, and I felt at every opportunity she was having a go at me. She was also dismissive of my symptoms and said 'it's nothing and happens'. The pain during my periods is excruciating and unbearable.

I have been prescribed Taramax. I feel I can ask questions and they do answer my questions, and explain things thoroughly. The service is not bad at all, but my first appointment was terrible. My first appointment there was an interpreter, I hadn't requested one but they had booked one for me.

During my last appointment they gave me advice and they did a scan. My symptoms were getting worse.

I found the clinic easily, and the waiting area is fine, clean enough. I wasn't informed of any delays to the clinic. The letters I receive for my appointments are just the standard letters, I haven't received any other information leaflets or anything."

Patient 3

"I have a urine problem. I have had since I gave birth to my baby boy. I went to my GP and they referred me here. The gynaecology doctor said to do pelvic exercise and said it might be because of my diabetes but I have diabetes for 25 years and I did not have any symptoms before. I've been coming here for at least 2 years now and there haven't done anything. Two months ago they gave me today's appointment. They are going to tell me when they will do the endoscope what the real problem is. Day by day my problem is getting worse I have requested them to do something or give medication. I have a tumour in my hand as well.

Patient 4

I have an appointment because I have a tumor in my stomach. I have been to my GP for stomach pain. My GP referred me here to gynaecology, they checked and did a CT scan but they didn't find anything. I went to Bangladesh and they did a full body checkup and find out I have a tumor in my stomach and it's big. Today I am going to see doctor and ask them to remove it because I am in pain and the tumor is getting bigger day by day. I am not feeling that well feeling very weak. I came here 3 or 4 times now and I'm not happy with the service or doctor, I am in pain for at least a year now and doctors not doing anything"

Patient 5

I had a miscarriage last week, I was 2 months pregnant. I have 2 children. This is my follow-up appointment just to see if everything is ok. I went to my GP with stomach ache, he referred me here they said there is no reason, it's normal. I am waiting for my urine test now. I felt they rushed me and didn't explain things properly. I wanted someone to explain properly what was happening and I wanted to ask questions like, when I am able to have my next baby. Waiting time is too long, they should have play area for the little ones."

Patient 6

"I have had problems with fibroids for about a year now. I saw my GP as it was gradually getting worse and causing anemia. I live in Barking and Dagenham and I couldn't get appointments at my local hospital King George's or Queen's hospital. I was referred back in April. After 6 months I received this appointment.

My fibroids were getting worse month by month. GP prescribed tablets to delay my periods so that I would have fewer of them. I also have type 1 diabetes. My glucose levels are up and down because of the pain. In September my blood levels went to 7, I contacted Queens for blood

transfusions, but they haven't got back to me.

I am also on iron tablets as I am always tired and lethargic. The first two days of my period I am unable to go out, I just stay at home, mostly in bed, because the pain is so severe. I am advised to take ibuprofen for the pain and it helps with the pain and cramps.

For this appointment, I just received a letter about the appointment, no further information or leaflets. I haven't been informed of any delays to the clinic, the receptionist was nice and pleasant.

Findings

There was general satisfaction with the staff and the quality of care that patients received.

The main issue raised related to patients understanding of their diagnosis and planned treatment. A number of outpatients seemed to be very confused about their care and who they should talk to find more information. Some did not feel that there was enough time to ask questions.

Prior notice that a female gynaecologist may not be available might also prevent wasted appointments.

Recommendations

1. Improve the administration processes both with patients and between professionals.
2. Make sure that patients understand the decisions surrounding their care and are clear who they can ask or where they can go to find more information about their diagnosis and condition.
3. Make sure that patients understand the referral process.
4. Signposting to a trusted NHS approved website that provided more patient focused information

and explanations of medical diagnosis and conditions would enable patient to better understand their conditions and be better patients.

5. Improve mechanisms to ensure that women gynaecologists are available for those patients for whom this is an absolute essential criterion for attending an appointment.

Initial Response from Royal London Hospital

In January 2020 the hospital opened eleven beds as winter surge beds. Which should reduce the need for patients to be placed on Ward 8C. We are also protecting day surgery and Emergency Gynaecology.

Ward 8C is being remodelled as a gynaecology and female abdominal surgery ward to try and reduce the huge variance in specialities cared for and to assist us in improving the quality of care for our patients and staff.

Acknowledgement

We would like to thank the staff at the Royal London Hospital who helped facilitate the visits and supported the volunteers to speak with patients on the ward. We would particularly like to thank Anna Mosesson, the Senior Sister on Ward 10E for her assistance.

Disclaimer

Please note that this report relates to findings from a limited number of patients that we heard from in 2019. Our report relates to specific visits to this service and is not representative of the experiences of all patients and staff, only an account of what was observed and contributed at the time.

This report is written by staff and volunteer Enter and View Authorised Representatives who carried out the visits on behalf of Healthwatch Tower Hamlets.

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