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Changes to chemotherapy services at
BHRUT: a review of patient experience by
Barking, Havering and Redbridge
Healthwatch

local healthwatch
working together

Introduction

The Healthwatch organisations from Redbridge, Havering and Barking and Dagenham were asked by the Outer North East London Joint Health Scrutiny Committee to gather the views of patients using chemotherapy services at Barking and Dagenham, Havering and Redbridge University Trust (BHRUT).

We recently held a focus group on Wednesday 27 March at Havering Town Hall, with patients and carers who had recent experience of using chemotherapy services at Queens and King George's Hospitals.

The service was changed in October without consultation and now provides chemotherapy from the Queens Hospital site in Romford.

Attendees

A total of **18** people attended the focus group. Healthwatch Barking and Dagenham also met with **two** people after the event as they were unable to attend on the day. Their numbers have been added to the figures below:

- **12** patients had received their chemotherapy at Queens Hospital
- **1** patient had received their chemotherapy at KGH
- **2** patients had received chemotherapy at both sites
- **5** carers or family members attended

Sunflower Suite and Mandarin B Ward (Queens)

Ward staff were *'really welcoming, nurses were great, amazing, caring, wonderful volunteers, professional and brilliant'*.

Most said there was a calm atmosphere, some told us they felt safe and supported. Most who had used the day unit said it was outstanding but felt it was very cramped. One patient who was on a clinical trial felt there was no privacy in the very limited space.

Some told us they were concerned that there was little privacy and had noted that since the changes last year, the beds seemed closer together to accommodate more patients using the space *'We're packed in like sardines'*.

All were still concerned that there was no natural light and many said this meant the lights were on all night.

Some patients told us they thought the section for younger patients was underused and empty at busy times. Some patients had taken it upon themselves to move into this section as they couldn't understand why it would be allowed to stand empty and place everyone into a small space.

Some felt privacy had become an issue with patients and family members saying private conversations could be overheard.

The use of student nurses was mentioned. All patients and family members said they understood and supported the use of student nurses but this had on many occasions led to a longer treatment session going from an average of 2-3 hours into 3-4 hours or more for some patients.

Most patients and carers said they had not seen new staff on the wards apart from student nurses. They felt staff were doing an excellent job under difficult circumstance, explaining that they felt staff were coping with additional patients and duties and had little time to chat to patients in between tasks. Some told us they knew of staff not taking their breaks in order to see to patient's needs.

A number of patients and carers said they felt the pressure on staff had increased when the shift pattern changed (longer day shifts) and they noticed a number of staff left at this time (they were uncertain whether this was as a direct result of the changes).

Most patients remained concerned that staffing levels were putting staff under increasing pressure. Some described the increased stress on staff had a 'knock-on' effect on them as it left them feeling uneasy about the service and standards.

One patient recounted an experience when they were given, without any warning or guidance or training whatsoever; a box of injections for five days by one of the nurses. They were told they were to inject themselves but offered no instruction or explanation. This was a cause of great stress and when they next met with their consultant, they explained what had happened. The consultant was very surprised.

Some patients and carers said they would have like more basic information about the ward, such as where you could get drinks etc (*'no one tells you'*).

Some wanted more comprehensive information at the start or prior to their treatment to understand what will happen. Most were in favour of more 1:1 personal services being offered as an option, *'Personalised care and support at all times would be good'*.

Two patients had received treatment at KGH whilst the move was taking place.

Both told us they were not formally informed about the changes. Both finished their treatment before the move.

Living with and beyond cancer hub - Cedar Centre

Four patients had used the Cedar Centre since it had opened in December last year. Ten patients and none of the four carers had heard of the services being offered but were interested to try them.

Of those that had used the services:

- None had used the weekly EMPOWER sessions.
- One had completed the HOPE course.
- None had used the carer's space.
- One had attended the Look Good Feel Better sessions.
- One had used complementary therapies.
- Three had attended for welfare advice but not at the Cedar centre (this was at Queens).
- No patients had received 1:1 psychology sessions at the Cedar centre although two patients had used a similar service at Queen's hospital.
- None had tried the art therapy/creative writing/relaxation or visualisation workshops
- One patient was about to begin attending the Myeloma support group.

All patients who had used the Cedar centre were pleased with the results.

The majority of patients and carers were unaware of the services on offer, with most saying they would want to take advantage of them.

Some patients said travelling to the Cedar centre could be an issue as they would be restricted due to school times or public transport.

Patient Transport

Most patients told us they were not offered patient transport.

One patient had been offered patient transport but said they had refused as they had not required it.

Parking Facilities

Most patients and family members who drove raised concerns about the parking facilities at Queen's hospital.

Most felt car parking costs should be free for all patients receiving long-term treatments, not just for chemotherapy patients. Some long-term

patients were aware that their carers could get a permit but this did not appear to be widely known. This kind of information should be provided as routine.

Many patients and carers expressed concern that part of the Sunflower Suite car park (about a quarter to a third) was currently housing a mobile Endoscopy suite due to a fire at the hospital a year ago. This presented major problems as the amount of spaces were always at a premium.

Clinic services

Although some patients felt the service had improved (*'Chemotherapy at Queens is done a lot more quickly; I see the same staff which is good.'*), a number of patients felt the service had become, at times, overloaded; (*'the clinic is more crowded; I used to go straight in at my appointment time, now I have to wait; the system is too overloaded to be efficient.'*)

Four patients told us they felt the service had changed in regards to raising medical issues when attending their chemotherapy sessions.

One patient explained that when they asked to speak to a doctor on the ward (Mandarin B) about a medical problem, not being sure whether it was related to their condition. They were told there was no doctor available and if they were concerned about the issue then they should go to A&E.

One patient told us they had small veins and this meant it was difficult when having blood test. Although the ward had given them a heat pad, they said there were not enough on the ward and other patients had resorted to bringing in their own heat pads.

Oncology Appointments

Some patients told us the system for making consultant appointments had changed. Where they had previously been able to make an appointment before they left the department; they now have to wait for a letter with their next appointment to be generated afterwards. This is leading to a delay in confirming the next appointment which is required before they next attend for the chemotherapy session.

Some patients and carers told us this was causing complications as not all the letters were arriving before their next booked chemotherapy session was due.

Some had resorted to telephoning the consultant's secretary to get their appointment details as, to attend the chemotherapy session, they needed

to have an appointment with their consultant a few days before their next session.

For some, this has meant they are worrying unnecessarily, or having additional tasks to remember. One said: ***'I shouldn't have to do this, I already have enough to think about!'***

Some told us when they contacted the secretary, they were told their appointments had not been booked. Although the secretary would tell them they ***'would fit them in'***; they were still concerned that this would mean they were being squeezed into sessions that were already very full and this meant further delays and long waits with some consultants having up to 30 patients to see at a session. One patient told us they had to insist on an appointment in order not to delay their next chemotherapy session, ***'If you're not assertive, you would be overlooked.'***

One patient told us they had been using the chemotherapy services for 6 years. However, in the last 6 months they have seen a big increase in the number of people attending at any given day they are there. They felt this had caused problems with their appointment times (being much longer). They were increasingly concerned that the number of people will have an impact on the quality of care

Another patient explained they were told they needed a blood transfusion and that it would be ready at 9.30am. When they arrived they were told it wouldn't be ready to at least 11am and that each of the two units would take 2 hours apiece.

One carer comment ***'Cancer patients don't know how long they have to live; our time is precious.'*** They added that the waste of time waiting around hospitals was unnecessary. They asked why they could not be contacted to let them know there was a delay so they could have come later.

Phlebotomy

Blood tests have become a concern for many commenting that they are having very long waits in the oncology department and have been attending other departments to get the test completed. Some said they can wait for up to three hours. One patient commented ***'The blood test department is sometimes too slow depending on the phlebotomist you have on. One in particular can take 20 minutes out of your time!'***

Some patients would like to see the service hours extended (currently 8.30am to 1.30pm) and additional staffing used.

One patient suggested the phlebotomy clinic could supply pagers to allow patients the opportunity to make use of the café at Queens and come back when it was their turn. ***Note: Pagers are currently used within outpatients departments and could possibly be made available with little effort or additional outlay.***

Chemotherapy Appointments

Some patients told us they were still concerned that their appointments were being booked too early and they were left to wait for 2 or more hours before their chemotherapy medication is ready.

Most said they couldn't understand why they were asked to attend the appointment at 9.30am but would not begin to receive their treatment until after 11am. ***Note: The use of pagers (see above) was similarly suggested for chemotherapy appointment delays.***

Some patients also stated they had been told the staff responsible for making up the chemotherapy medication do not start work until 9am therefore they couldn't understand why they would need to be in the department for 9.30am as it takes time to create and dispense the product.

One patient told they were booked to attend a CT scan at KGH as the scanner at Queens was not being used. They had difficulty getting a cannula inserted as the department was unable to do this, even though they had called ahead to notify them of their need. They asked if they could go to Cedar Ward to get this done, only to discover it had recently closed.

Pharmacy

Some patients felt the time taken to receive their chemotherapy prescriptions should be addressed. One patient told us they have been asked if they wished to wait but, when they asked how long it would take, they were told it would be over four hours. This patient had school aged children which meant it would have been impossible to stay there as they had to collect their children from school. Although they asked to be contacted, they were not.

They later tried to telephone the pharmacy only to find out the number they had originally been given was wrong.

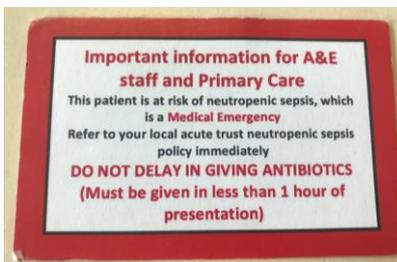
Questionnaire

Some patients said they were being contacted after their appointments to complete surveys over the phone.

Although they didn't mind doing this, they felt the information they were being asked was repetitive and any issues or concerns did not seem to be passed on when they attended their next appointments which meant they had to repeat themselves.

Accident and Emergency

A major concern was highlighted in regards to the use of chemotherapy priority cards (see images below) when accessing Accident and Emergency Department at both Queen's and KGH.



A number of patients provided examples of problems when they have had to attend A&E and identify themselves as a chemotherapy patient receiving treatment.

Although they were all issued with a 'red card' by their oncology consultant; they were not prioritised as they had expected within the first hour due to their increased risk of sepsis.



Some patients had been expected to wait for over two hours. In one case, a patient and their family member had waited over four hours to be seen and triaged within Queens A&E department.

Patients were very concerned that they were being asked to sit in A&E and Urgent Care Departments without being prioritised due to the high risks of infection associated with their treatment.

Two patients reported being told to 'take a seat' next to patients who were vomiting and clearly very unwell. At least three patients told us they resorted to waiting outside the department (in the winter months) for many hours before being seen. One said, *'The 'Red Card' is useless and doesn't give (chemo) patients priority.'*

The majority of patient and carers spoken with who had experience of using A&E raised similar concerns about accessing emergency services when being treated with chemotherapy.

Many raised concerns that the A&E departments at both hospitals seemed reluctant to contact the oncology department to ask for further

information. One patient told us they took it upon themselves to contact the oncology department when the A&E clinician refused to do so.

Patients have been told to go to A&E if they have a problem with their condition but many told us they would like to contact the ward directly for support as they were unconvinced that A&E was the best place to receive appropriate support. One patient told us they had such poor experiences attending A&E on two separate occasions, they had begged their partner not to take them.

One patient told us, ***'I'm scared of A&E at Queens as they're not specialised in cancer care.'***

They continued; ***'I went to A&E after my third (chemotherapy) treatment as my temperature had soared. I had to explain the issue to four doctors! They had no knowledge of the risk to oncology patients.'***

These issues were raised with BHR CCG at their governing body meeting on Thursday 28 March 2019 and escalated to Healthwatch England to identify whether other Healthwatch organisations had heard of similar concerns.

Some patients also told us they were concerned that when then had attended A&E, they were treated by clinicians with very little experience of using a PICC line¹.

One patient said 'The staff at A&E didn't know how to take blood from the PICC line. They were about to take it from my toe but my wife had to stop them and pointed out that a chemotherapy patient can't have blood taken from their toe.' Note: blood was not taken from the toe.

¹ PICC: (peripherally inserted central catheter line) - Note: PICC lines are used to give someone chemotherapy treatment or other medicines. A PICC line is a long, thin, hollow, flexible tube called a catheter and normally put into one of the large veins of the arm, above the bend of the elbow.

Recommendations

- **Accident and Emergency**

The main concern to emerge from the event was the apparent lack of familiarity of staff in both Urgent Treatment Centre and the mainstream Emergency Departments, with the specific healthcare needs of patients undergoing treatment for cancer.

We recommend as a matter of urgency, clinical leads from urgent and emergency care meet their counterparts in oncology to agree protocols for dealing with cancer patients who hold red cards and require urgent or emergency treatment to ensure that their cancer treatment is not compromised in any way.

- **Sunflower Suite and Mandarin B Ward (Queens)**

The lack of privacy, cramped space and lack of natural light needs to be addressed by the Trust. Patients are undergoing treatments which can be quite traumatic. Having conducive surroundings has a huge impact on the wellbeing of patients undergoing lengthy treatments.

- **Patient Transport & Parking Facilities**

Patients and carers should have access to parking when they need it. If the car park is required for other purposes, we would recommend the Trust identify how they could ensure patients can access other parking facilities free of charge.

All patients should be assessed for patient transport.

- **Oncology Appointments**

We recommend the system for booking patient appointments is reviewed. Patients should be able to confirm their next appointment before leaving the department.

- **Chemotherapy Appointments**

We recommend the system for booking chemotherapy appointments is reviewed to ensure patients are booked in appropriately and not made to wait unnecessarily. Patients should not have to wait for long periods of time when they could be booked in later in the day.

If appointments are being offered before 9.30am, medication should be ready to be administered.

- **Questionnaire**

Information and issues identified through surveys and questionnaires should be addressed. Patients should feel listened to and valued for their opinion.

- **Phlebotomy**

We would **recommend** that phlebotomy services are reviewed to understand where a better service could be initiated.

- **Clinic services**

Patients should be able to ask for additional clinical support when they are attending clinics and not be sent to Accident and Emergency or Urgent Treatment Centre.

As previously stated, patients have raised concerns that Emergency Department clinicians do not always have the right level of experience to respond to the specific healthcare needs of patients undergoing treatment for cancer.

- **Cedar Centre**

Patients who have used the new ‘Living with Cancer and Beyond Hub’ have rightly praised it, however we **recommend** that more patients need to be made aware of the opportunities. More publicity and information should be made available to patients attending Queens Hospital.

We were however, concerned that the diversity figures presented by the Trust are not representative of the local populations particularly in Redbridge and Barking & Dagenham. Although we are aware a patient has the choice to use these services, we would **recommend** the Trust review the types of services being offered to identify why they are not being used by particular community groups.

- **Pharmacy**

Patients should be given better information and support to access pharmacy services. No patient should be asked to wait for a prescription if it will take over four hours to prepare. Better systems should be in place to allow patients to return to collect their prescription at a suitable time.

If patients are required to contact the pharmacy, the Trust must ensure contact details are continually reviewed and updated.

- **Patient Engagement**

We **recommend** the Trust review the way patients and carers are involved in the development of the service. The Trust told us they had engaged with some patients who were previously using cancer services but we were not able to confirm whether they were recent users of current services.

Most patients and carers we spoke with told us they were not actively engaged with during the service change and would welcome the opportunity to have an input into the proposals.

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Contact Details:

Healthwatch Redbridge

Cathy Turland - Chief Executive Officer

020 8553 1284

cathy@healthwatchredbridge.co.uk

Healthwatch Barking & Dagenham

Richard Vann - Healthwatch Officer

0800 298 5331

richard@healthwatchbarkinganddagenham.co.uk

Healthwatch Havering

Ian Buckmaster - Executive Director

01708 303300

ian.buckmaster@healthwatchhaverling.co.uk