Transforming Cancer Services Team for London

Improving patient experience

Travel and transport support for cancer patients undergoing chemotherapy and radiotherapy - Recommendations for commissioners.

May 2016
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Executive Summary

The experience of cancer patients travelling to hospital for their cancer treatment, mainly chemotherapy and radiotherapy, varies considerably. Patients have reported struggling with the stress and costs of public transport and were private transport is used the costs of parking in London are extremely high. When hospital transport is used for eligible patients, journeys are often long and patients are required to be ready several hours before their appointment adding to the anxiety and stress of going for cancer treatment. There needs to be reliable up to date information and provision available at the Trusts to support cancer patients with excessive costs and/or difficulties with travelling to hospital for their chemotherapy or radiotherapy treatment. Clinical Commissioning Groups (CCGs) need to ensure that cancer patients can travel to hospital for their treatment without undue costs or difficulties, especially with the consolidation of cancer services across London.

The Transforming Cancer Services Team (TCST) for London undertook a mapping exercise to review the information and support given to patients on travel and transport provision and support for patients receiving chemotherapy and radiotherapy at London and West Essex Hospital Trusts. The mapping identified gaps in the information and support given to chemotherapy and radiotherapy patients by the hospital in relation to local transport and travelling to hospital for treatment. This has been used to develop a set of recommendations for CCGs to consider, once understanding the side effects of chemotherapy and radiotherapy on patients undergoing treatment, the associated risks to their health, as well as the financial costs that could escalate. This work will also inform Transport for London with the intention of influencing the information and support they offer their customers who travel regularly to hospital for treatment.

The set of recommendations which have been developed for consideration are:

1. Cancer patients undergoing chemotherapy and radiotherapy should have access to comprehensive up to date information and support on travelling to hospital and all transport provision offered by the Trust.

2. Cancer services / Trusts should display comprehensive up to date information for patients and inform their patients of the support available before they start their treatment.

3. Trusts / cancer services should ensure that cancer patients undergoing treatment at the Trust are made aware of any concessions for travel, transport and parking, and the process for reimbursement.

4. Trust should ensure that the process for claiming back expenses is simple and accessible for cancer patients and their carers.

5. Hospital Trusts, located within the congestion charge zone, should inform patients, who are too ill to travel on public transport, of the support they can offer and display
this information at the Trust. The reimbursement process should also be explained.

6. CCGs should to understand the potential difficulties faced by cancer patients travelling to hospital regularly to undergo chemotherapy and radiotherapy treatment. CCGs should further explore the experience of these patients and the impact this has on their health and wellbeing, especially with the consolidation of cancer services across London.

7. CCGs should collaborate with Local Authorities informing them of parking signage around hospital sites so that patients do not struggle to obtain parking when attending hospital on a regular basis for treatment.

8. TCST to inform Transport for London of the needs of cancer patients undergoing chemotherapy and radiotherapy, which may contribute to the work on supporting patients when travelling on public transport to hospital for on-going intensive treatment.
Introduction

London has one of the largest urban transport networks, with integrated bus, river and road systems spanning the city's 32 boroughs. However, travelling to and from hospital for cancer treatment can be tiring and expensive, especially if a patient is undergoing treatment on a daily basis over a period of time. A patient's health and wellbeing can be compromised and the costs quickly add up, which can inadvertently cause further distress.

There is help and support available for cancer patients, however the extent to which this information is made available to patients is varied across London. Hospitals, cancer services and local services can do more to ensure patients receive more comprehensive information and support during this period.

It's difficult to predict exactly what side effects a patient will experience while having chemotherapy and radiotherapy. Different people react to treatment in different ways. A small number of people have very few or even no side effects, however many patients do feel unwell, in particular stressed and tired, as well as the potential changes in appearance that a patient may or may not have expected. Having chemotherapy / radiotherapy can affect a patient's short-term as well as long-term physical and emotional health and wellbeing.

While the side effects of chemotherapy can be distressing, most don't pose a serious threat to a patient's health. However, occasionally, some side effects can be very serious. For example, if a patient has a rapid fall in white blood cells, they may be vulnerable to a serious infection. People having chemotherapy for cancer of the blood cells or bone marrow are most at risk of developing serious infections. This is because this type of cancer will already have caused a reduction in the number of white blood cells. Neutropenia is a low level of neutrophils, a type of white blood cell. All white blood cells help the body fight infection. Some level of neutropenia occurs in about half of people with cancer who are receiving chemotherapy. It is a common side effect in people with leukemia. If a patient develops neutropenia they need to pay close attention to personal hygiene to lower your risk of infection.

Nausea and vomiting are common side effects of chemotherapy. They affect around half of all people being treated. If a patient experiences nausea and vomiting, they will be given medication (anti-emetic) to help control their symptoms. Side effects of anti-emetics include constipation, indigestion, problems sleeping (insomnia) and headaches.

If a patient's immunity has been affected there are some precautions they can take to help avoid infection. These include:

- avoiding people who have an infection
- avoiding places where there is a risk of picking up an infection
- avoiding crowds
- checking with the doctor before having any vaccines
- maintaining a high standard of personal hygiene
- protecting the central or PICC line (if a patient has one) from bacteria and damage
- keeping the mouth clean
- avoiding certain foods that may contain harmful bacteria.
Patients may be advised to take extra precautions, such as avoiding crowded places and using public transport at busy times.

Radiotherapy affects different people in different ways and it is difficult to know exactly how a patient will react to the treatment. For some people, side effects are mild, while others experience more severe effects. Some side effects begin during treatment or straight afterwards, whereas others can appear weeks or months afterwards. Most side effects of radiotherapy only last for a few days or weeks after treatment has finished. However, some, such as tiredness or hair loss, can last a few months.

A patient might feel very tired during their radiotherapy treatment. This is because the body has to repair damage caused by the radiotherapy to healthy cells. If a patient has to travel to their treatment each day, they may get even more tired. Some patients feel like having a sleep 1 to 2 hours after each radiotherapy treatment. This tiredness is called fatigue and patients may also feel weak as though they have no energy. Tiredness can still be a problem for some months after treatment has finished. Therefore the main side effects of radiotherapy treatment include tiredness and weakness, sore skin and loss of hair in the treatment area.

Fatigue is one of the most common and distressing side effects of cancer and its treatment. Fatigue from cancer treatment is often more intense than the feelings of being tired we all have from time to time. Research suggests that most people receiving cancer treatment will experience fatigue. Cancer related fatigue is very different from everyday fatigue. Cancer related fatigue is worse, it lasts longer and sleep doesn’t make it better. It’s unpredictable and many people describe it as overwhelming, affecting every part of their lives.
Perspectives of patients with lived experience

Several patients with lived experience were asked to provide examples of their experience to contribute to the development of this area of work. Their experience and views on the need for more targeted transport and travel support for cancer patients when undergoing treatment for chemotherapy and radiotherapy have been summarised.

**Colorectal cancer patient**

Using public transport became impossible for me because of the lack of toilets, Colorectal cancer surgery can leave you a bit (or a lot) incontinent, and on top of that radiotherapy and chemotherapy can give you bad diarrhoea. This means that you need to open your bowels frequently and urgently. You no longer have the capability to 'hold it in' until you reach a toilet; it just comes out. Even when you try to take precautions like wearing incontinence pads, double pairs of underwear, carrying a spare clean pair of trousers or skirt with you, you still need to find a toilet ASAP to clean up and change your trousers.

And then there was the extreme tiredness and sometimes it being very painful to sit, let alone walk. All it takes is for one set of escalators on the tube to be out of order and you have to abort the journey. You don't have the energy to climb stairs, and even if you try, you have to climb them slowly one foot at a time. In rush hour you simply can't do this when other people are in a hurry, pushing past you, running up the stairs two at a time, not understanding why you're blocking their way.

In the end, when I was at my worst my dad had to drive me to and from Barts every week (Friday morning) from my home in Middlesex. It took a long time in traffic and was very expensive, but there was no choice. Mum would put a duvet and a cushion on the back seat so I had a makeshift bed in the car. Sitting up straight was too painful because of my wounds so I had to lie down on my side. Every speed bump on the road would cause a jolt of pain.

I often used to wonder, and still do, what happens to all the people who don't have a dad with his own car? Do they spend a fortune on taxicabs? Or do they not go for the treatment they need because it's just too hard to get to hospital?

In my clinical practice today, my oncology patients regularly complain about hospital transport. They need to be ready by 7am to be picked up even though their appointment time isn't until hours later. And they have no access to food, drink, or toilet facilities as they drive around in heavy London traffic picking up all the other patients, not all of whom are ready and waiting. They arrive at the hospital exhausted, before treatment has even begun. And when a long day of chemo is over they often have to wait 2 hours in the cold patient transport lounge waiting to go home. It becomes a tiring and long 12 hour day for them. And to make matters worse their relatives can't travel alongside them on hospital transport - they have to make their own way to and from the hospital, leaving the poor patient all alone on the journey.
**Breast cancer patient**

When I had breast cancer in 2010 I had radiotherapy. I was feeling sick and suffering from fatigue as well as emotionally very tearful. This meant when I was travelling with my husband in the car as he is disabled along with my son, they would both get very stressed and anxious about me feeling this way. This affected their behaviour and as a result I suffered lack of sleep. I was fortunate that I spoke to my radiotherapy nurse and she put me in touch with the Manager for radiotherapy. They were able to organise a taxi to the hospital and back for me. This was extremely helpful and relieved the stress from my husband and son.

**Chronic myeloid leukaemia patient**

I am unusual as I live with a chronic cancer. I take a chemotherapy pill daily and have done since January 2007, I could be on it for the rest of my life. A side effect of my treatment is chronic fatigue. I have never lost my hair, or looked ill. This has its plus sides and it's negative. The main negative one is that I look fine even when I don't feel it. I never get offered a seat on the tube or the bus and have been glared at for not giving up my seat to someone who visually needs it more than me. This has been a big struggle for me. Sometimes I feel brave enough to ask, but in general I keep quiet as I don't feel like announcing to a tube carriage that I have cancer and need to sit down.

I have recently come across the man who has made 'cancer on board' badges on twitter and he is posting me a badge so I can wear it on the bus/tube. I hope that this means I get offered a seat more often and that people are more forgiving when I don't stand up. Time will tell.
Evidence of the need for further support with travel and transport for cancer patients undergoing treatment

There are a number of ways patients may be able to get help with travel and parking costs:

- If a patient receives certain benefits, they may be able to claim a refund on transport fares to hospital for treatment.
- Some areas have local schemes that help with transport fares to hospital, including the Highlands and Islands Travel Scheme in Scotland, and the Isles of Scilly Travel Cost Scheme.
- If a person is visiting a close relative or partner in hospital and they receive certain benefits, they may be able to get help with your travel costs through the Social Fund.

Hospital parking policies vary. Some hospitals in England have reduced parking costs for people with cancer. In Scotland and Wales, parking is generally free, with a few exceptions. In Northern Ireland, parking is free for people receiving chemotherapy and radiotherapy.

Many hospitals have concessions for people with cancer, but they are not always well publicised. Cancer services and Cancer Information and Support Centres should readily offer information on the hospital’s car parking policy and the concessions available to cancer patients whilst undergoing treatment.

London has the London Congestion Charge Zone where there is a charge to travel within central London at certain times of the day. If a patient has a Blue Badge they automatically do not have to pay the charge. However, these patients will have to make a one-off payment of £10 to register for this discount. If a patient has to pay the congestions charge to get to and from hospital during their cancer treatment, they should be able to claim this money back from the hospital. A clinician would need to confirm that the patient is too ill to travel on public transport and the patient would need to keep hold of their receipt to show they have made the congestion charge and then go through the process at the hospital to obtain the refund. This process can be difficult and timely if the service at the hospital is limited.

Examples of good practice

Wiltshire cancer patients get personal transport for treatment

Cancer patients from Wiltshire who need to travel to Oxford for radiotherapy are being offered individual transport to and from their appointments. About 700 patients a year have to make the 60-mile round trip, the NHS said. The move is aimed at minimising the discomfort associated with long journeys for people having treatment.

By providing access to individualised transport, individuals will have the option to travel to Oxford and back in much greater comfort meaning that any patient who is currently receiving radiotherapy treatment will experience reduced travel and waiting time."

Sharon Jennings, of Franklin Gardens, who made her final trip to Oxford for treatment last
month, stated the funding boost was good news for patients. "Luckily, I had my nephew and my brothers who took it in turns to take me," said Sharon, 44, who travelled to Oxford for treatment for five weeks. "If it wasn't for them, I would have had to use the hospital transport and you are told a time to be ready - not when you necessarily will be picked up - and you have to wait for that knock on the door. It's uncomfortable and it's a long way to go if you're on your own."

Sharon also said the fact the new travel arrangement would allow patients to take family members along would be a big help. "My mum came with me each time but if you used the hospital transport, you haven't got the comfort of bringing a family member with you."

"It's quite a lonely experience - it's not something you look forward to."

**Daft as a Brush Cancer Patient Care**

Daft as a Brush Cancer Patient Care offers staffed custom-made vehicles to transport outpatients, free of charge, to and from Hospital who are undergoing chemotherapy and radiotherapy cancer treatment.

The regions that are covered by Daft as a Brush are: Northumberland, North and South Tyneside, Durham, Newcastle upon Tyne and surrounding areas. There is no charge to the patients for the service. The service entails collecting and transporting the patients in a safe and comfortable environment, from where they are living, taking them to where they will be having their treatment. If required staying with the patient whilst they have their treatment and then bringing them back home in readiness for their next course of treatment.

Daft as a Brush Cancer Patient Care is a free service for cancer patients and is totally funded by donations and the hard work done by their amazing volunteers. It costs approximately, £100,000 per year to run the Daft as a Brush service.

**Cancer Cars Scotland is a database of volunteer driving schemes for cancer treatment in Scotland**

The website (http://www.cancercars.co.uk) is designed to assist health professionals, people with cancer, their relatives and friends to find voluntary organisations in Scotland which provide a personal transport service to hospital appointments.

The website has been set up by a GP who runs a small charity which takes people with cancer to hospital appointments. If anyone would like to start a similar organisation in their area she would be very happy to give any support and advice.
Cancer patient invents 'Baby on board'-style badges for sick passengers on busy Tube services

A cancer patient has designed a new "Baby on board"-style badge to help people like him get a seat on busy Tube services.

James McNaught, 45, spent three gruelling months using the London Underground to get from his home in Kentish Town to University College Hospital after he was diagnosed with throat cancer in 2014. The civil servant spent hours struggling to find a seat as he was not visibly unwell and could not speak because of his treatment.

His innovation, which Transport for London has expressed an interest in, gives other cancer patients the opportunity to wear "Cancer on board" badges when they ride the network.

Mr McNaught told the Standard: "I couldn't talk as I had radiotherapy in my throat. There was no way I could make myself understood short of writing notes. I had to travel feeling like that and the horrific amounts of morphine I was prescribed made me appear drunk. When I got onto the Tube, I kind of got the feeling people were thinking I was a junkie. It was embarrassing and difficult. "I just huddled up in the corner and hoped no one was looking at me too much.

Mr McNaught has created around 100 badges for cancer patients to test out. "The thing about cancer is everybody is terrified of it and it's a club that nobody wants to join but once you are part of it, everyone looks out for you and that's where the idea for the badges came from," Mr McNaught added. "If I'd have had one of those badges when I was going through that treatment, it really, really would have helped."

A Transport for London spokesman said: "We understand asking for a seat on the Tube can sometimes be difficult, which is why we produce products such as our baby on board badge so passengers in priority seats know when they should give them up.

"We are also aware that some of our customers may have a hidden condition, which requires them to be seated, and we are currently looking at every available option to help improve their journey. We will be looking to discuss Mr McNaught's idea further with him."

Non-emergency patient transport services

Some people are eligible for non-emergency patient transport services (PTS). These services provide free transport to and from hospital for people who have a medical need for it.

A patient's GP or the healthcare professional who referred them to the hospital can discuss with them whether they have a medical need for transport. Patient transport services may not be available in all areas.
Help with travel costs

If a patient is referred to hospital or other NHS premises for NHS specialist treatment or diagnostic tests by their doctor, dentist or other health professional, they may be able to claim a refund of reasonable travel costs under the Healthcare Travel Costs Scheme (HTCS).

To qualify for help with travel costs under the HTCS, patients must meet three conditions:

Condition one: At the time of their appointment, the patient or their partner (including civil partners) must receive one of the qualifying benefits or allowances listed below, or meet the eligibility criteria of the NHS Low Income Scheme.

Condition two: The patient must have a referral from a healthcare professional for a specialist or to a hospital for further NHS treatment or tests (often referred to as "secondary care").

Condition three: The patient’s appointment must be on a separate visit to when the referral was made. This applies whether their treatment is provided at a different location (hospital or clinic) or on the same premises as where your GP or other health professional issued the referral.

The NHS organisation handling the claim will base any refund on the basis of what would have been the cheapest suitable mode of transport for the patient's circumstances, which can include the patient’s age, medical condition or any other relevant factors.

This means the patient should use the cheapest, most appropriate means of transport, which in most cases will be public transport. If they travel by car and the claim was approved, the patient would be reimbursed for the cost of fuel at the mileage rate used by the local CCG. The patient will also be able to claim for avoidable car parking and toll charges. When using a taxi for transport, it is recommended that the patient agrees this in advance with the hospital or CCG before they travel. Patients in London may be able to claim congestion charges operated by Transport for London.
Mapping London provision - Support for cancer patients undergoing active treatment

The Transporting Cancer Services Team (TCST) carried out a mapping exercise of the travel and transport information and support that is available for cancer patients during their chemotherapy and radiotherapy treatment. The mapping consisted of reviewing every NHS London Trust and West Essex NHS Trusts website to log the different types of information and support they offer cancer patients undergoing treatment. Lead Cancer Nurses were also contacted at every Trust and asked to provide further specific information on the information and support cancer services are able to offer chemotherapy and radiotherapy patients, as well as the challenges their patients face with this issue. All this information has been recorded onto a spreadsheet for commissioners and policy makers to consider. The mapping exercise additionally consisted of reviewing good practice from around the country where additional support is provided to cancer patients undergoing chemotherapy and radiotherapy, as well as reviewing the literature that is available from the NHS, cancer charities and the Transport for London websites.

The full set of findings from the mapping exercise is available in the Appendix.

The main findings showed that all hospital websites gave comprehensive information on travelling to the hospital by public transport. Where hospitals have parking facilities, this information was also available along with car parking charges in nearly all Trusts. Hospitals that offer concessions and exemptions for disabled people, and in some cases cancer patients undergoing chemotherapy and radiotherapy treatment, had this information clearly available on their Trust’s website, however, this was only approximately half of all Trusts across London. 10 out of 21 Trusts highlighted that they offered concessions or exemptions for parking for cancer patients undergoing treatment. These hospitals were;

Barking Havering and Redbridge University Hospitals NHS Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Epsom and St Heller University Hospitals NHS Trust
Imperial College Healthcare NHS Trust
Lewisham and Greenwich NHS Trust
London North West Healthcare NHS Trust
North Middlesex University Hospital NHS Trust
St Georges Healthcare NHS Trust
The Hillingdon Hospitals NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust

Those hospitals which fall into the congestion zone also offered information on claiming back the fee either directly on their Trusts website or by signposting to the Transport for London website. These included;

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<th>Hospital Name</th>
<th>Description</th>
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<tr>
<td>Barts Health NHS Trust</td>
<td>Signposted to Transport for London site</td>
</tr>
<tr>
<td>Guy’s and St Thomas NHS Foundation Trust</td>
<td>Very comprehensive information on claiming back the charge from the Trust</td>
</tr>
<tr>
<td>University College London Hospitals NHS Foundation Trust</td>
<td>Very comprehensive information on claiming back the charge from the Trust</td>
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</table>
Patients on certain benefits may qualify for help with travel costs under the Healthcare Travel Costs Scheme (HTCS) however only a few Trusts displayed this information on their websites. Nearly all the Trusts had information on their websites regarding non emergency hospital transport and the eligibility criteria for this service.

From the feedback received from the Trusts, cancer services were able to provide further information where they were able to support patients during chemotherapy and radiotherapy with travel and transport needs. These included:

<table>
<thead>
<tr>
<th>Trust</th>
<th>Information</th>
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<tbody>
<tr>
<td>Barking Havering and Redbridge University Hospitals NHS Trust</td>
<td>Offers support through the Macmillan grant process for anyone who is struggling to meet travel costs.</td>
</tr>
<tr>
<td>Barts Health NHS Trust</td>
<td>Offers support to patients who may wish to apply for a Macmillan grant. Sometimes cancer services will access other funds via their Samaritan funding.</td>
</tr>
<tr>
<td>St Georges Healthcare NHS Trust</td>
<td>Specific written information on ‘Help with travel costs - cancer services’ and ‘Car parking concession policy - includes chemotherapy patients’. Macmillan Information Centre, site specific CNS and Chemotherapy Day Unit nurses also provide information and assistance with referrals for blue badges, taxi cards and Macmillan grants.</td>
</tr>
<tr>
<td>University College London Hospitals NHS Foundation Trust</td>
<td>Verbal advice is given where patients are advised to avoid public transport and crowds, but some have to travel to clinic in rush hour. Patient information leaflet for ‘Help with hospital travel costs’ available. Specific patient groups such as allogenic stem cell transplant patients are provided with transport for the three month post-transplant period.</td>
</tr>
<tr>
<td>The Princess Alexandra Hospital NHS Trust</td>
<td>Patients can use a voluntary service, Ambulance Car Service Volunteers (these are a group of volunteers who offer their time and vehicle to help patients attend their appointments). The Trust also uses UCLH transport for patients going there for PETs, EBUS and surgery, but this only applies to inpatients and the process for booking is not simple.</td>
</tr>
<tr>
<td>The Whittington Hospital NHS Trust</td>
<td>Occasionally can request for a parking permit for a few months but these are limited and visitors of critical care patients and for relatives travelling long distances have priority. Patients on means-tested benefits can claim back travel expenses (cheapest mode of transport) from the hospital cashier. Help is offered to some patients to claim blue badges, disabled persons freedom passes and taxi cards. However not all patients are eligible and it can take 6-8 weeks for forms to be processed.</td>
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Additional information which is available from the NHS, cancer charities and the Transport for London website are:

- We are Macmillan Cancer Support - Benefits and other financial support - Help with transport and parking (travel to and parking at hospital, public and local transport, the Blue Badge Scheme, help with car or driving costs).
- Transport for London - Are you eligible for Congestion Charging NHS reimbursement?
Recommendations for commissioners

The following recommendations have been drawn from reviewing existing information and support available for cancer patients undergoing chemotherapy and radiotherapy treatment, and the structures and systems currently in place to support cancer patients undergoing treatment. These are intended to inform commissioners in the commissioning of cancer services, inform service improvement, and aims to be a useful resource for providers of services.

1. All cancer patients undergoing chemotherapy and radiotherapy should have access to comprehensive up to date information on travelling to hospital and any transport support offered by the Trust / cancer services, especially with the consolidation of cancer services across London.

2. Cancer services / Trusts should display comprehensive up to date information for patients and inform patients of any support available before they start their chemotherapy / radiotherapy.

3. All Trusts / cancer services should ensure that all cancer patients undergoing treatment at the Trust are made aware of concessions for travel, transport and parking, where available, and the process for reimbursement.

4. Trust should ensure that the process for claiming back expenses should be simple and accessible for cancer patients and their carers.

5. Hospital Trusts which are located within the congestion charge zone, should inform patients, who are too ill to travel on public transport, of the support they can offer and display information for claiming back the congestion charge within the Trust. They should also explain the process for reimbursement.

6. CCGs need to understand the potential difficulties faced by cancer patients travelling to hospital regularly to undergo chemotherapy and radiotherapy treatment, from the side effects of treatment to the financial strain this can put on the patient and their carer. CCGs should further explore the experience of patients traveling to hospital to receive regular treatment and the impact this has on their health and wellbeing, especially with the consolidation of cancer services across London.

7. CCGs should collaborate with Local Authorities informing them of parking signage around hospital sites so that patients do not struggle to obtain parking and are clear about restricted local permit holder bays (e.g. blue badge parking for local residents only) so they don't accidentally park in these spaces and get fined.

8. TCST to inform Transport for London of the mapping exercise and the needs of cancer patients undergoing chemotherapy and radiotherapy. This may contribute to their work on supporting patients when travelling on public transport to hospital for ongoing intensive treatment.
**Action and next steps**

- Transforming Cancer Services (TCST) for London will share recommendations and the report with the London Strategic Planning Groups’ cancer work streams:
  - **East London** - Integrated Cancer Group
  - **North East London** - Barking and Dagenham, Havering and Redbridge Cancer Collaborative
  - **South East London** - Cancer Strategy Group
  - **South West London** - Cancer Clinical Design Group
  - **North West London** - Central London, West London, Hammersmith and Fulham, Hounslow and Ealing Clinical Commissioning Groups and Brent, Harrow and Hillingdon Clinical Commissioning Groups
  - **North Central London** - Primary Care and Prevention Board

- Strategic planning groups (SPGs) are asked to disseminate the report to CCG cancer strategy groups and consider recommendations at a sub-regional level.

- TCST Cancer Commissioning Managers and Cancer Performance Managers to highlight to CCGs the recommendations and report. CCGs are requested to consider the learning and recommendations and the potential for local service developments and improvements with their cancer providers. Where feasible and appropriate the recommendations will be incorporated into local commissioning and provider strategies.

- TCST will share the recommendations and report with the Pan London Cancer User Partnership (PLUCP) who have been instrumental in identifying the support needs of cancer patients whilst undergoing cancer treatment. The PLCUP will continue to highlight the need for comprehensive information and support in their wider engagement work.

- TCST will share the recommendations and report with the Charity Partners, a collaboration of cancer charities who work with the TCST to improve patient experience for people affected by cancer across London.

- TCST will share the recommendations and report with Transport for London who have supported the work of a cancer patient with regards to traveling to hospital for cancer treatment. It is hoped that this report will contribute to the on-going work to improve customer experience for people with hidden / long-term conditions.
### Appendix

#### Mapping of information and support on travel and transport for cancer patients undergoing chemotherapy and radiotherapy

<table>
<thead>
<tr>
<th>Hospital Trust</th>
<th>Information on Trust website</th>
<th>What type of information is available</th>
<th>Where is the information located</th>
<th>Any information missing</th>
<th>Feedback from Lead Cancer Nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barking Havering and Redbridge University Hospitals NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Queens and King Georges Hospital. Cycle routes. Public transport routes. BHRUT travel plan. Cash Free Buses leaflet. Parking and charges + disabled, concessions and reimbursement for cancer treatment.</td>
<td>Home - For patients and visitors - Queens/King Georges - Getting there</td>
<td>Hospital transport services.</td>
<td>The Trust does not currently offer additional support to patients with travel, although they recognise that this is an area that requires improvement. Patients on low income or some benefits can claim back their travel costs by taking their appointment cards, travel receipts and evidence of low income/benefits to cashier. Apart from hospital transport which is booked on medical grounds cancer services have no other way of offering help with travel. They do offer support for patients through the Macmillan grant process for those that are struggling. They do have a car park for oncology patients, adjacent to the oncology department, which is free to those on treatment.</td>
</tr>
<tr>
<td>Barts Health NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Barts, Royal London, Newham, Mile End, Whipps Cross. Parking and charges + disabled parking. Mention of congestion charge but sign</td>
<td>Home - Our hospitals</td>
<td>Hospital transport services. No detailed information on reimbursement for the congestion charge and the service</td>
<td>At Barts we offer the patient transport service that the Trust use and also sometimes ask if patients wish to apply for a MacMillan grant that might help cover some transport costs if they are not eligible for hospital transport or prefer not to use it. Otherwise we sometimes access other funds via our Samaritan funding.</td>
</tr>
<tr>
<td>Chelsea and Westminster Hospital NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Chelsea and Westminster and West Middlesex. Parking and charges + disabled, concessions and reimbursement for chemotherapy patients / regular outpatient appointments. Patient transport services.</td>
<td>Home - Your visit - Getting here / Information for patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Croydon Health Service NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Croydon Hospital. Parking and charges + disabled, concessions and reimbursement for illness. Patient transport services.</td>
<td>Home - Contact us / For patients and visitors</td>
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</table>

Cancer services do not offer chemotherapy or radiotherapy at Croydon University Hospital. Cancer services would always offer advice and/ or signposting to Macmillan info services for patient advice.
<table>
<thead>
<tr>
<th>Trust</th>
<th>Information</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Epsom and St Helier University Hospitals NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Epsom and St Helier. Parking and charges + disabled, concessions and reimbursement for cancer treatment. Patient transport services.</td>
</tr>
<tr>
<td>Guy's and St Thomas' NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Guy's and St Thomas'. Parking and charges + disabled. Help with travel including comprehensive information on claiming back the congestion charge. Patient transport services.</td>
</tr>
<tr>
<td>Homerton University Hospital NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to the Homerton. Parking, charges + disabled information. Patient transport service information leaflet.</td>
</tr>
<tr>
<td>Imperial College Healthcare NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to all their hospital sites. Parking and charges + disabled. Patient transport services.</td>
</tr>
<tr>
<td>King's College Hospital NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to King’s and the other sites. Parking and charges + disabled information. Patient transport services.</td>
</tr>
<tr>
<td>Kingston Hospital NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Kingston. Parking and charges + disabled information. Patient transport services.</td>
</tr>
<tr>
<td>Lewisham and Greenwich NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Lewisham and Queen Elizabeth. Parking and charges + disabled information. Patient transport services.</td>
</tr>
<tr>
<td>London North West Healthcare NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to Central Middlesex Hospital, Ealing Hospital, Northwick Park and St Mark's Hospital. Parking and charges + disabled information. Car parking</td>
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concessions for cancer patients. Help with travel costs. NHS hospital transport services.
| Royal Brompton and Harefield NHS Foundation Trust | Comprehensive travel and transport information. | Public transport information for getting to the Royal Brompton and Harefield Hospital. Parking + disabled information. Patient transport services - non emergency hospital transport for patients + eligibility. | Home - About the Trust - Contacts and locations – Brompton / Harefield transport / Non-emergency transport | Car parking charges |
| Royal Free London NHS Foundation Trust | Comprehensive travel and transport information. | Public transport information for getting to Barnet, Chase Farm and Royal Free. Shuttle bus. Parking and charges + disabled parking. Hospital travel cost scheme. | Home - Contact us - Getting to our hospitals / Parking at our hospitals | Hospital transport services. No information on concessions. |
| St George's Healthcare NHS Trust | Comprehensive travel and transport information. | Public transport information for getting to St George's and other hospital sites. Parking and charges + disabled information. Car parking concessions policy - includes chemotherapy. Help with travel costs for eligible patients. Patient transport services - non-emergency patient transport. | Home - Contact and find us - Find us / Help with travel costs / Car parking concession policy | At St George’s Cancer services do not have a specific leaflet or other document relating to transport to and from chemotherapy appointments. However information is given to patients and their carers relating to hospital transport and availability of parking onsite; including information relating to the reduced onsite parking costs available for Chemotherapy appointments. We would also inform patients of where to access information relating to the controlled parking zone around the hospital where pockets of cheaper parking can be accessed. The Macmillan Information centre, site specific CNS and Chemotherapy Day Unit nurses also provide information and assistance with referrals for blue badges, taxi cards and Macmillan grants to assist with travel costs. Unfortunately none of this information is available in leaflet form. The cancer CNS and medical/clinical oncologists also provide contact details and some access information for transport to RMH for radiotherapy appointments. |
transport services. Other transport solution - taxi card, community transport service, etc...
<p>| The Princess Alexandra Hospital NHS Trust | Comprehensive travel and transport information. | Public transport information for getting to Princess Alexandra and other hospital sites. Parking and charges, concessions + disabled information. Free parking for chemotherapy patients. Help with travel costs. Hospital transport services. | Home - Getting to us Home - Visitor’s information - Hospital Transport | At Princess Alexandra Hospital it appears that the main problem is in collecting patients following chemotherapy. They arrive on time but are often not collected until 3-4 hours after their treatment has been completed. So this results in an awful lot of time that patients are left sitting around and often the nurse has to stay late to remain with the patient until they are collected. The patients can use a voluntary service, Ambulance Car Service Volunteers...these are a group of volunteers who offer their time and vehicle to help patients attend their health service appointments. The Trust also uses UCLH transport for patients going there for PETs, EBUS and surgery. PAH transport will have nothing to do with it unless they are an in-patient. We have a request form that is faxed to UCLH but no confirmation of booking is received either to us or patient so there is always a great deal of anxiety about whether the transport will turn up or not. It frequently doesn’t. Not sure how we will request when faxes go. There is a telephone assessment number for transport but patients are usually refused transport on this. Transport issues continue to be very stressful for patients (and us!) and time-consuming. Would be great if it could be sorted and a smoother pathway No paperwork given out (we have none) as usually telephone contact with the patient at this stage and often timing doesn’t allow. Patients going to North Middlesex Hospital for Radiotherapy use their transport. Again no information is given to patients (could be given at OPA if we had it). Usually works well but there are occasions when it fails. |</p>
<table>
<thead>
<tr>
<th>The Royal Marsden NHS Foundation Trust</th>
<th>Comprehensive travel and transport information.</th>
<th>Public transport information for getting to all the Royal Marsden sites. Parking and charges information. Help with travel costs. Patient transport services.</th>
<th>Home - Contact us - How to get to the Royal Marsden Home - Your care - Support services - Patient transport / Financial, employment and benefits help</th>
<th>No information on concessions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Whittington Hospital NHS Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to the Whittington. No / very limited parking on site and limited disabled parking - any charges are highlighted. Useful links and contacts for travel and transport. Help with travel costs. Hospital transport services.</td>
<td>Home - Patients and visitors - Getting here / Help with travel costs / Patient Transport</td>
<td>No information on concessions.</td>
</tr>
<tr>
<td>University College London Hospitals NHS Foundation Trust</td>
<td>Comprehensive travel and transport information.</td>
<td>Public transport information for getting to UCLH and other hospital sites. Limited disabled parking available. Surrounding parking information + charges. Booking Transport. Reclaiming transport fares. Assisted travel for disabled passengers. Congestion charge. Useful links and contacts for travel and transport. Help with travel costs. NHS hospital transport services.</td>
<td>Home - Services - Our hospitals</td>
<td>This was looked at 18 months ago and the advice at that time was verbal advice so just checking this is the same advice and whether it is also given in written information (like in their chemo record books). At the time the Trust checked with GSTT and RMH, and they had the same issues at the time - i.e. patients advised to avoid public transport and crowds, but some will still have to attend clinics in rush hour. Specific patient groups such as allogenic stem cell transplant patients are provided with transport for the three month post-transplant period. From our Support and Information Service we have had anecdotal feedback from patients that travel is very difficult and often cancer patients look well, but the hidden consequences such as fatigue/nausea make standing for long period on the tube difficult.</td>
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