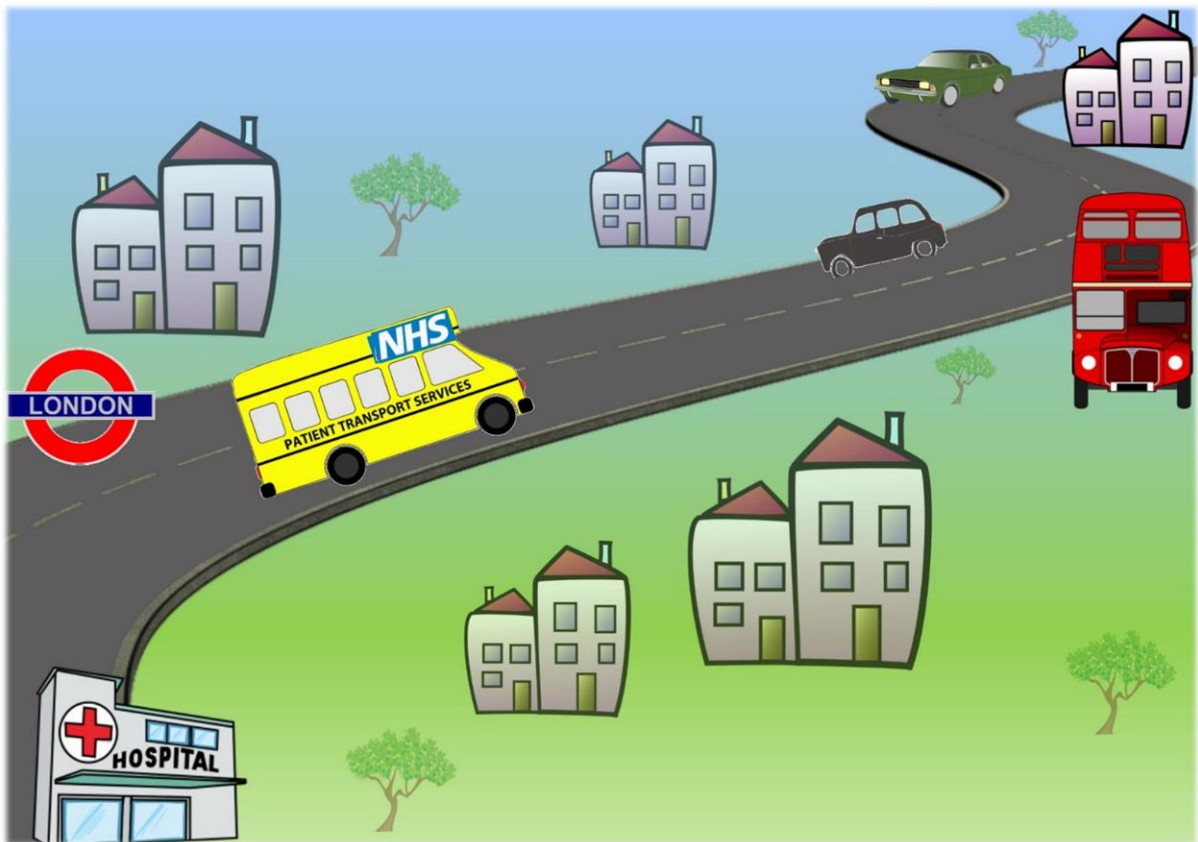


# Patients' Experiences of Transport to Cancer Appointments Barnet



**October 2017**

# Contents

INTRODUCTION.....	3
BACKGROUND.....	3
National and Local Picture .....	3
Current Local Support Initiatives .....	3
METHODOLOGY .....	4
Data Collection.....	4
Data Analysis.....	5
FINDINGS.....	5
Profile of Respondents.....	5
Transport.....	6
Service User Feedback and Comments.....	7
Challenges .....	7
Individuals’ Suggestions to Improve Cancer Transport Services .....	8
Key Discussion Points.....	8
RECOMMENDATIONS .....	10
REFERENCES.....	11
ACKNOWLEDGEMENTS.....	12
APPENDIX I .....	13
APPENDIX II .....	15

## INTRODUCTION

Healthwatch Barnet was established through the Health and Social Care Act 2012 to give users of health and social care services a powerful voice both locally and nationally. Healthwatch Barnet was established in 2013 and is part of a national network led by Healthwatch England.

We listen to people's views about Barnet health and social care services, the good and the bad. If there are concerns about the quality or safety of services, or there are unmet needs, we feedback patient's experience, to local commissioners and decision makers, in order to improve the service.

Following feedback from some local residents about issues they had faced in travelling to cancer appointments, we decided to learn more about the patient experience of cancer transport services. We looked at the NHS England national survey on the cancer patient experience, and the recommendations from the Cancer Commissioning Board Patient Advisory Group work. We were keen to learn about the patient experience of travelling to cancer appointments in and from Barnet. Healthwatch Barnet's Community Outreach and Research Team was able to utilise its existing positive contacts and a range of outreach sessions in a variety of venues.

*Note: All respondents who took part in our research, are anonymous.*

## BACKGROUND

### National and Local Picture

The recent 'National Cancer Patient Experience Survey 2016' shows patients have had an 'increasingly positive experience about their NHS cancer care'. This includes an improved experience of being seen as soon as patients thought necessary for hospital cancer appointments, tests and treatment. On a scale of 0-10 (10 is very good), patients in Barnet rated their overall experience as 8.6 in 2016, which is a slight improvement on the 8.5 in 2015. However, the overall experience in Barnet is slightly worse than the 2016 England average rating of 8.7.

Areas that Barnet Clinical Commissioning Group (CCG) scores better in than the England average include: "patients find it easy to contact a Clinical Nurse Specialist" (87% compared to 86%) and "patients feel treated with dignity and respect" (91% compared to 88%). Areas that Barnet scores worse than the England average, include: "patients feel that GPs did everything they could to support them (90% compared to 94%)" and "hospital staff told them who to contact if they are worried about their condition after they left hospital" (61% compared to 62%). For further details, please refer to Cancer Patient National Survey, 2016.

The survey does not ask any questions about the use of transport or mode of travel to appointments and treatment. Rather, this Healthwatch report sheds light on the patient experience of cancer transport services, which is not captured elsewhere.

### Current Local Support Initiatives

In addition to receiving feedback on transport services, we explored some local initiatives which are in existence to support individuals travelling to cancer appointments.

- **Transport for London (TfL)** carried out research in 2015 into the experiences of people with less visible disability getting a seat on public transport. As a result of this research, TfL created a badge 'please offer me a seat'. Around 1,200 customers were recruited to take part in a six-

week trial<sup>1</sup>. Approximately 72% of journeys made by people trialling the badge were made easier, and 86% felt more confident when asking for a seat. In April 2017, 'please offer me a seat' was formally launched. To date, more than 20,000 badges have been issued. Individuals, who feel that they would benefit from having a seat more readily, can apply for a badge online or by phone, free of charge, without having to provide any proof of their a disability or particular circumstances. The aim is, that by noticing the badge, the public will offer a seat to those in need when trains are busy.

- **Chai Cancer Care** is a registered charity that provides support to individuals from the Jewish community, who are affected by cancer. In Barnet they offer a pick-up service to enable individuals to attend the support centre, but not hospital appointments. The pick-up service is run by volunteer drivers who have experienced cancer (either personally or through supporting a relative/friend). Some individuals find working with drivers with lived experience of cancer comforting and reassuring. The volunteers are recruited and trained by Chai.
- **Advocacy in Barnet** is a Barnet charity that provides advocacy support for local residents aged 50+ who use health and social care services. They received some funding from Barnet Cancer Link (a charity that aims to help cancer patients and their families through their journey), to provide a transport service for cancer patients. They set up an agreement with two minicab companies to offer transport services, free of charge for the user, to and from appointments. Eligible service users are 50+ years of age, have a cancer condition, and are a Barnet resident. Around 100 people used this service and the project was very successful, however funding has been used so it is no longer operating. We have included two case studies (see **Appendix I**) to explain how individuals have benefitted from the service.

## METHODOLOGY

### Data Collection

A steering group of Healthwatch Barnet staff and four Healthwatch volunteers was set up to look at the best way to gather feedback from local people about their experience of cancer transport. Some of the group met with both the Commissioner for North Central London CCG Cancer services and the Senior Operations Manager for Oncology Royal Free, who were helpful in supporting the design of the investigation.

The steering group designed a questionnaire, which was also set up as an online survey. The survey targeted people who had been through cancer treatment either personally or supporting a friend or relative, within the last two years. The survey was promoted online through various channels and social media. The Royal Free Cancer Services assisted with distributing the questionnaire to patients undergoing chemotherapy. The group also visited Cherry Lodge Cancer Care and North London Hospice services to undertake the survey with service users directly.

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<sup>1</sup> Information was obtained from TFL Accessibility Team, by email, on 15<sup>th</sup> August 2017.

## Data Analysis

Under the following findings section, we have presented an analysis of quantitative survey data. Qualitative feedback and comments received from service users have been analysed and compiled.

## FINDINGS

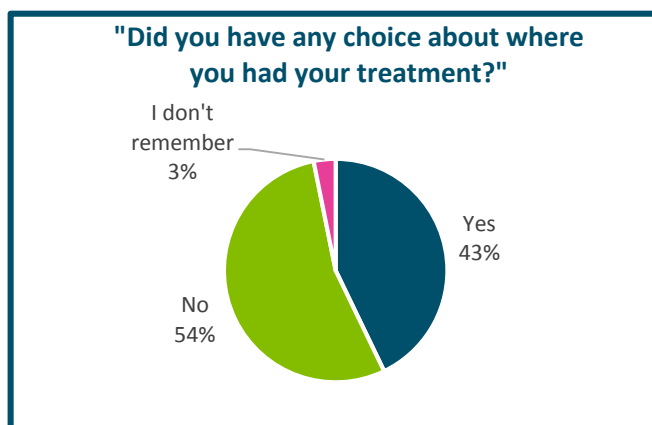
We received a total of 68 responses to the survey. Of these, 10% were aged 30-49, 42% 50-69 and 43% ages 70 and over. 97% of respondents answered questions relating to where they lived, revealing that 75% of respondents were Barnet residents, while the remaining 25% lived outside of the Borough, but use/d Barnet based services.

### Profile of Respondents

The majority of respondents attended Barnet Hospital (36%) as their main treatment hospital, followed by the Royal Free Hospital (32%) and University College Hospital (17%). The breakdown of the main hospitals respondents attended can be found in **table 1**. More respondents (43%) received their treatment from one hospital compared with those that receive it from two or multiple hospitals (26% and 31% respectively).

**Table 1. Main hospital attended for treatment by respondents**

Hospital	Number of Respondents
Barnet Hospital	24
Royal Free Hospital	21
University College Hospital	11
North Middlesex	2
Royal Marsden	2
Mount Vernon	2
Chase Farm	1
Finchley Memorial	1
Guy's Hospital	1
London Clinic	1
<b>Total</b>	<b>66</b>



We asked people if they had been given a choice of where they wanted to have their treatment. Over half (54%) of respondents said they had not been given a choice compared with 43% who said they were given a choice.

A large proportion of the respondents were receiving or had received treatment for breast cancer (40%), prostate cancer (16%) and lymphoma (6%). 32% of respondents were receiving treatment for “other” cancers and 6% for more than one type<sup>2</sup>.

## Transport

Nearly all participants (67 people) answered the questions relating to transport to and from cancer treatment appointments. In response to the question “how do/did you generally travel to and from your cancer treatment?” public transport was found to be the main mode of transport used by 41% of respondents. 26% of respondents travelled with a family member or friend and 14% drove themselves to the appointment. 1% of respondents had used transport provided by a support group or charity. **Table 2** shows the breakdown by mode of transport.

**Table 2. Main mode of transport to and from cancer treatment**

Mode of Transport	% of Respondents
Public transport	41%
Taken by family or friend	26%
Drive one’s self	14%
Private taxi	8%
Hospital transport	6%
Other (mainly walking)	4%
Transport by a support group/charity	1%

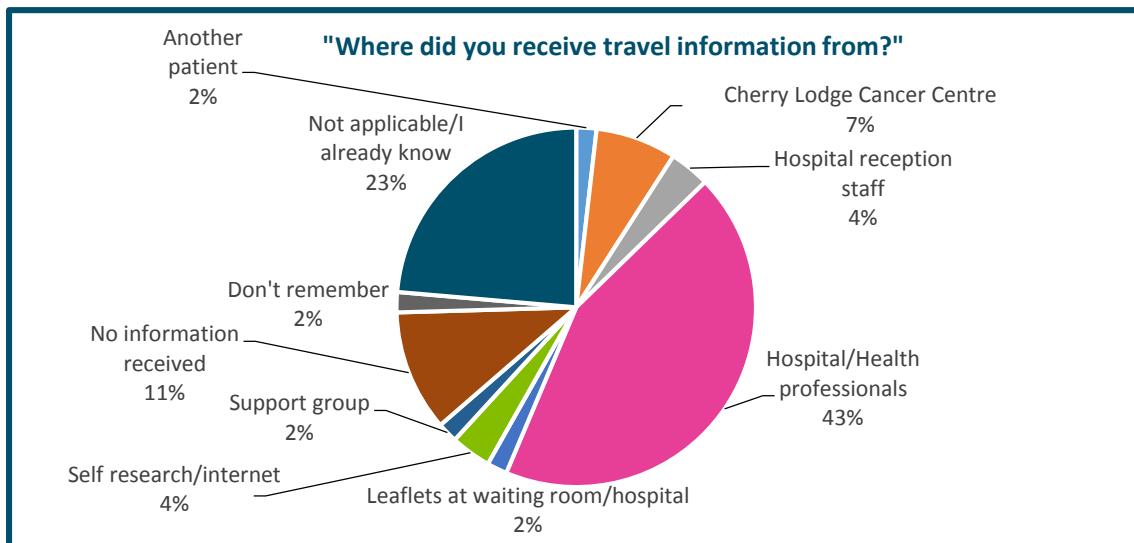
We asked participants if they felt they had received sufficient information about travelling to appointments/treatment at the appropriate time. This included for example, information relating to fares. The majority of respondents did not feel they were given sufficient information. **Table 3** shows the respondents answers to whether they felt they had been given sufficient information.

**Table 3. Responses to receiving sufficient information about travel**

Answers	% of Respondents
No, I did not feel I was given sufficient information	53%
Yes, I was given sufficient information	37%
Yes, but it was confusing	2%
I don’t remember	2%
Not applicable (mainly, I use a Freedom Pass so I did not need information)	6%

<sup>2</sup> See Appendix II for a detailed breakdown of types of cancer respondents receive/d treatment for.

When asked about where they received information about travelling from, (55 respondents answered), 11% said they had received no information. Of those who did receive information, the majority (43%) received it through the hospital or health professionals.



## Service User Feedback and Comments

Through discussions with patients we were able to see in depth what challenges service users face, along with their suggestions for improvements. Some of the service user feedback/comments have been collated below, including challenging and positive experiences. Once surveys and interviews had been completed, a number of discussion points emerged.

### Challenges

#### Public transport

- Daily/weekly trip on public transport is very long and stressful
- Using public transport is tiring, stressful and is a long journey
- Unable to get a seat on public transport
- Using public transport is non-hygienic which could pose a risk to patients especially if they are undergoing an immunotherapy treatment

#### Hospital transport

- Using hospital transport is tiring and stressful with a long journey, and a long wait for pick-ups/drop-offs
- Long wait for hospital transport
- Long journey using hospital transport (up to 10 hour day)

#### Parking

- Parking is difficult, even with a cancer pass (i.e. a permit that gives cancer patients a priority for parking at hospital)
- Parking is expensive
- Quite difficult to have to renew parking pass every month

#### Cost of travel

- Using taxis for regular appointments is very expensive, up to £50 per journey to Central London
- Public transport is expensive, up to £20 per day (including travelling with a companion)

### Other

- Difficult to ask family/friends to give me a lift to appointments on a regular basis

### Positives

- Provided with hospital transport which is convenient for me
- Public transport has excellent connections
- Transport services, such as Cancer Link, provide private, quick and more affordable transport

### Individuals' Suggestions to Improve Cancer Transport Services

- To have dedicated cancer parking space at hospital sites, with sufficient spaces
- To have private transport after the operation
- To have access to a minibus or a Dial a Ride service
- To have more funding for volunteer drivers to support patients
- To have reduced taxi rates/discounted transport, that would operate door to door
- To publicise information, more widely, about transport, options available and how travelling could affect one's condition as it progresses
- To have assisted transport to appointments
- To not have to explain oneself every time a patient books transport
- To have palliative care to manage pain while travelling
- To have a reliable transport that is available when needed
- To get reimbursed for travel expenses for a patient's travel buddy

### Key Discussion Points

**Individual's awareness of travel preparations:** More than half (53%) of respondents did not feel they were given enough information about transport at the right time. Patients would benefit from having a comprehensive brief on what to expect on travel time and assistance, how travelling can affect their body, and whom to call for support when going through treatment. They would also benefit from getting information at the right time, which may not be when they receive their diagnosis.

**Hospital staff are key in providing travel information:** Nearly half (46%) of participants said that they received information from the hospital, including healthcare professionals and reception staff. Hospital and other health settings are the first to provide travel information for newly diagnosed cancer patients. It is imperative that patients receive basic guidance from both hospital clinicians and reception staff to provide information about where to find cancer transport services. This includes access to support groups and charity transport, the TfL badge, how to prepare for travelling, and how commuting can affect one's health and mobility.

**Experience of travel mode:** Some patients drive themselves to appointments or travel independently at the start of their treatment, however, as their condition progresses they tend to feel weaker. They therefore appreciate or rely on assistance of a friend or a travel buddy to accompany them. For example, one patient, with a brain tumour, sometimes has seizures while travelling on public transport, which makes it unsafe if travelling alone. There is a mixed experience of using charity, private taxi, public transport, and hospital transport services. Many patients feel that they have to repeat and explain themselves, when they book a transport, as to why they need their transport to be needs-specific, while others feel that they are understood. Some private taxis do not offer a ramp for wheelchair use. Sometimes, it is difficult to get a seat on public transport and delays, which are often reported, results in arriving late to appointments.



**Cost of travel:** Most patients who responded did not receive financial support towards their travel expenses. Costs, depending on the mode of transport, could amount to nearly £20 per day for public transport, and up to £50 for private taxi. Some patients have a bus pass because it is cheaper to use, but do not have a travel card for the tube, which is more expensive. Regular travelling to appointments is very expensive for patients over the course of their treatment. If patients are in receipt of named welfare benefits they should be able to be reimbursed for travel expenses. Macmillan Cancer Support provide advice on entitlements, however, the majority of patients who responded to our survey did not qualify for help in this way. Family and friends who often accompany patients also find it expensive to travel regularly using public transport to accompany the patient.

**Frequent need to attend multiple treatment sites:** 57% of respondents said that they travel to 2 hospitals or more, with many patients reporting that they travel to central London for treatment. Many patients travel to different sites, either to have a blood test, a diagnostic test, radiotherapy or chemotherapy, or other form of treatment. This can be very stressful especially when patients are feeling weak or unwell. It was seen to be much less stressful if all tests and treatment were on the same site.

**Travel distance to hospitals:** Some patients said that they travelled for more than one hour, or several hours. This is either because the hospital is a long way from home, public transport experiences delays, or hospital transport has many pick-ups during the day which could mean up to 8 hours of travel time including the full journey to and from appointments.

**Time off work:** Where patients are working while going through treatment, they told us it can be difficult to take time off work in order to attend and travel to appointments.

**Voluntary-sector support:**

- **Limited awareness of charity transport support:** While their experience was very positive, only 1% of patients said that they had used transport arranged by a charity or a support group. This could be due to the lack of awareness of support services are available, especially when most patients receive transport information from their health professional.
- **Preference for support group/charity transport:** Patients, who use transport services coordinated by a support group or a charity, are usually satisfied, compared to using a hospital transport. They find charity transport to be a more convenient service to use, quicker to respond, a shorter journey to take, and available for a private use. They also find it more affordable, compared to a private taxi, more hygienic than public transport; and more independent than relying on family and friends.
- **A holistic approach to support:** Through using a charity support service, a patient has access, not only to a transport service, but also to a social and community support network, if needed.

This report does not address the possible adverse effects of cancer patients' issues with transport to and from treatment centres. It may be that recovery is impaired and/or patients do not continue with their treatment. Apart from health issues there may be increased costs when patients do re-present or whose treatment outcome is sub-optimal.

## RECOMMENDATIONS

- To consider working with public transport services and Transport for London to ensure that information is being disseminated in health and social care settings to offer patients the use of badge 'please offer me a seat', and to encourage passengers give up their seat for badge holders 'please offer me a seat', either through the display of posters or support of TfL staff.
- To consider commissioning travel buddy schemes, including reimbursing family and friends, working with the voluntary sector, to assist patients in their travelling specially those who use public transport and long journeys.
- To explore ways to make appointments available close to a patient's home or place of work, whenever possible.
- To ensure sufficient guidance and information is provided to enable patients feel prepared for travelling long distances, for example, on how to travel, what to expect while travelling, how to prepare for travelling as treatment progresses, and to provide a named contact to give information at the right time when needed.
- To ensure that staff/volunteers are trained, and prepared to assist a cancer patient with their travelling, providing care and understanding, without having the patient to explain their condition.
- To ensure that sufficient parking spaces are available for cancer patients, when attending all of their appointments including treatment and consultations.
- To discuss palliative care with patients to manage pain while travelling.
- To ensure and to discuss assistive equipment or tools with patients to manage their mobility, for example, providing Zimmer frame.

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## ACKNOWLEDGEMENTS

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- Chai Cancer Care
- Cherry Lodge Cancer Care
- North London Hospice
- Royal Free London Hospital, Cancer Team
- Transport for London (TfL)
- Healthwatch Barnet volunteers – Stewart Block, Margaret Singer, Diana Abramova and Margaret Peart.

## APPENDIX I

### Case Studies showing patient experiences using the Cancer Link Barnet Service, run by Advocacy in Barnet

#### Case Study 1 – A vital service when other travel options become too difficult

Mr X is a 66 year-old man with lung cancer and bone metastases. He first heard about the service from a neighbour who had seen the service advertised on StreetLife - an online social community website. He has a loving and supportive wife (they will soon be celebrating their 40th anniversary) and she usually accompanies him to his appointments despite not being in good health herself. He has undergone a lengthy course of chemotherapy and immunotherapy but unfortunately there has been no alleviation of his symptoms and the lesions are growing. His condition is now affecting his voice.

The bone cancer was concentrated in his left thigh and hips and he has not been able to drive since January 2016 (his wife does not drive). He was using public transport but as a result of his fatigue found the walk from the tube station to one hospital very challenging.

Before using the Cancer Link service he had been relying on friends and neighbours. He has used Uber cars, but felt too exhausted to organize the multiple journeys involved in his treatment to several locations in the Borough of Barnet, e.g. the Royal Free, Finchley Memorial, Chase Farm and Barnet General.

He was worried about the dirty state of public transport when he was immunosuppressed by his treatment and the overcrowding on tubes and buses and said this was “a brilliant system” particularly when the weather was really hot. There are also exorbitant parking charges to consider at some of these sites (as well as the stress of finding a space).

He would qualify for hospital transport, but this frequently entails a considerable wait for the journey home and this is extremely tiring and stressful, especially as the journey itself usually takes ages, dependent on traffic and whether or not there are any other pickups/drop offs when “going around the houses”.

Mr X and his wife did not want to know how long he might have left but were “taking each day as it comes”.

### **Case Study 2 – A thank you note from a mother**

“I just wanted to drop you a line to thank you for allowing my daughter and myself (as her escort) to book minicabs for her hospital appointments through the Cancer Link Transport scheme.

My daughter’s main hospital is in London and parking is nigh on impossible. We are unable to use public transport due to her condition. She has an inoperable brain tumour which causes her to have frequent seizures, making it very unsafe to use the Underground.

We do qualify for hospital transport, but this frequently entails at least a 2 hour wait for our journey home and this is extremely tiring and stressful, especially as the journey itself usually takes an hour or so, dependent on traffic and whether or not there are any other pickups/drop offs en-route.

Being able to book a cab, which will turn up to collect us within a very reasonable time and which is just for ourselves, makes a huge difference to our day. My daughter is much more relaxed, which has a direct effect on the number of seizures she has.

Once again, many thanks, and I hope you are able to continue to offer this fantastic service into the future”

## APPENDIX II

What type of cancer did/do you receive treatment for?

Prostate	16.4%
Skin	0.0%
Breast	40.3%
Renal	0.0%
Upper gastrointestinal	1.6%
Lower gastrointestinal	1.6%
Lung	4.5%
Head and neck	3.3%
Testicular	0.0%
More than one type	6.0%
Brain	1.5%
Kidney	3.0%
Bone Marrow	3.0%
Pancreatic	1.5%
Lymphoma	6.0%
Colon	1.5%
Bladder	1.5%
Multiple Myeloma	1.5%
Ovarian and Pelvis	1.5%
Windpipe	1.5%
NET	1.5%
Thyroid	3.0%

