TOWER HAMLETS
JOINT STRATEGIC
NEEDS ASSESSMENT
FOR CANCER (JSNA)

GUIDANCE ON EVIDENCE, STRATEGY
AND PRACTICE
1. EXECUTIVE SUMMARY

- Cancer is the largest cause of death in Tower Hamlets, and accounts for a third of all deaths in people under 75 years. Although the incidence rates for cancer are similar to the England average, standardised rates for mortality are higher and for survival are lower. There are around 665 new cancer cases each year, and 300 deaths, more than half of which are premature, in people under 75 years old.

- There are inequalities in cancer outcomes including patient experience, between Tower Hamlets and England, and within Tower Hamlets between different population groups. The ability to positively influence cancer incidence and outcomes sits across health and social care domains, including public health, primary, community and secondary health care services, and social care.

- More than 4 in 10 cancers could be prevented by making changes such as not smoking, keeping a healthy body weight, cutting back on alcohol, maintaining a healthy diet and being physically active. Prevention is a key focus in reducing cancer and the recurrence of cancer. Since 2013, the mortality rate from preventable cancers in Tower Hamlets has reduced to closer to the national rate, but continued effort is needed to improve this further.

- Outcomes are improved when cancer is diagnosed and treated earlier. Measures related to early diagnosis in Tower Hamlets show low public awareness of cancer, low uptake of cancer screening, later stage diagnosis and cancer waiting times standards not fully met. More work is needed to increase participation in screening, increase public awareness of cancer, to support GPs to diagnose cancer earlier and to improve pathways in primary and secondary care.

- While treatment indicators are similar to national standards, some responses to the annual national patient experience survey show that patients in Tower Hamlets have worse experience.

- People living with and beyond cancer have diverse needs. One in 4 people who has been treated for cancer lives with ill health or disability as a consequence of their treatment, and 75% have one or more other long term conditions. The integrated care programme in Tower Hamlets aims to support around 3,600 residents with a cancer diagnosis.

- More than 40% of people with a palliative care need have cancer. End of life care for this group should be person-centred, holistic and integrated. It aims to improve quality of life and to enable self-care. Place of death is regarded as a marker for quality of care, indicating patient choice. A higher proportion of deaths in Tower Hamlets (including people with cancer) occur in hospital compared to the England average, and fewer people die in their usual place of residence.

- Interventions in line with the national and local strategies are in place or planned in Tower Hamlets. These aim to reduce the incidence of preventable cancers; to increase survival and to reduce mortality from cancer; and to improve the health and wellbeing of people affected by cancer, including meeting their psychosocial needs.

- Recommendations for local action have been made from this needs assessment
2. RECOMMENDATIONS

Reduce the incidence of preventable cancers

- by supporting people to stop smoking, reduce alcohol intake, be more physically active and maintain a healthy weight
- by supporting people to take up HPV and Hepatitis vaccination and to participate in cervical and bowel screening

Detect cancer earlier and increase survival from cancer

- by increasing public awareness of cancer, reducing barriers to presenting to a GP and increasing the take up of cancer screening
- by reducing delays in referral in primary care; increased access to investigations, use of decision support tools, shared learning from audit and significant event analysis
- by reducing delays in secondary care through improved referral pathways for investigation and assessment
- by reducing the risk of recurrence in people living with and beyond cancer, by supporting them to be more physically active, as well as making changes also relevant for primary prevention

Improve the health and wellbeing of people affected by cancer

- by improving patients’ experience of care
- by providing the Recovery Package for people treated for cancer (holistic needs assessment, treatment summary and support to take up health and wellbeing opportunities)
- by ensuring that primary, secondary and social care services are joined up and responsive to individual needs
- by helping to meet the psychosocial needs (including financial) of people affected by cancer
- by supporting people living with and beyond cancer to manage the long term consequences of treatment

Improve the quality of care at the end of life for people who die from cancer

- by supporting people to express their preferences about care at the end of life
- by ensuring that people’s preferences are shared appropriately so that they can be met, particularly where people would prefer not to die in hospital
- by continuing to provide specialist palliative care services in community, hospital and hospice settings to meet the individual needs of patients and their families
- by providing comprehensive multi-agency training to improve the skills and confidence of everyone who supports people in their last years of life
3. NOTES ON DATA USED IN THIS DOCUMENT

KEY TO COMPARISONS

Compared to average: 🟢🟢🟢 Better  🟢🟢 Grey Similar  🟢🔴🔴 Worse

AGE STANDARDISATION
Age-specific rates of a subject population (in this case Tower Hamlets) are applied to the age structure of a reference population (in this case the European standard population) to give a standardised rate per 100,000 people. The age-standardised rate allows comparison between populations with different age profiles.

DESCRIPTION OF SIGNIFICANCE
We estimate how well the measured sample represents the entire population using 95% confidence intervals. If the measurement could be repeated it would be within the same bounds 95 out of 100 times. If the ranges of two confidence intervals do not overlap, this is evidence that the two populations are statistically significantly different, ('better' or 'worse'). However, if the confidence intervals overlap the difference between the two populations could be due purely to chance. In this case we say the populations are similar. Where the population is small, the confidence intervals may be large and quite different numbers will be statistically similar.

Indicators with this icon are from the 2015 NHS National Cancer Patient Experience Survey
4. INTRODUCTION
Cancer is the leading cause of premature death in Tower Hamlets. One in two people born after 1960 in the UK will develop cancer at some point in their lives. People are living longer, and more people will be diagnosed with cancer in their lifetime. There is an urgent need to strengthen health and social care services to work together to manage the needs of the growing and ageing population. This is in addition to the expectations for better methods of diagnosis, treatments, and earlier diagnosis outlined in the National Cancer Strategy. Prevention plays an important role in the concerted effort needed to reduce the impact of cancer in coming decades.

The UK’s cancer survival has doubled over the last 40 years and around half of patients now survive the disease for more than 10 years. Meanwhile, the proportion of people who survive cancer continues to lag behind rates in countries with comparable health systems. But as more people benefit from improved healthcare and longer life expectancy, the number of cancer cases is expected to rise. In London 235,500 people were living with and beyond a diagnosis of cancer in 2013 and this figure is expected to reach 387,000 by 2030. For many people, cancer is another long term condition (LTC) - and people with cancer are likely to have other LTCs which need to be managed alongside the short, medium and long term effects of cancer treatment - all of which affect their quality of life.

The ability to positively influence cancer incidence and outcomes sits across health and social care domains, including public health, primary, community and secondary health care services, and social care.

**Patients are 3 times more likely to survive cancer when it is diagnosed later**

WHAT IS THE POLICY CONTEXT?
The National Cancer Strategy 2015-2020 builds on the previous cancer strategies, and its priorities align with the current Five Year Cancer Commissioning Strategy for London 2014-2019. Key objectives of the London and National strategies are:

- **prevention of cancer** through supporting population approaches to healthy behaviour and increasing screening uptake
- **increasing survival from cancer** through earlier detection, improving referral and diagnostic pathways and ensuring access to optimal treatment
- **reducing inequalities in outcomes from cancer** by reducing variation in access to optimal diagnosis and treatment across population groups and localities
- **improving patient experience** through integration of health and social care services, ensuring that patients and families are better informed, empowered and involved in decisions around their care
- **improving the health, wellbeing and quality of life for patients after treatment and at the end of life** through commissioning services based on health and wellbeing outcomes, with a population
focus. This includes secondary prevention to reduce recurrence of cancer and the impact of the side effects of treatment.

LOCAL STRATEGIC CONTEXT
Cancer is the largest cause of death in Tower Hamlets, and accounts for a third of deaths in people under 75 years. Although the incidence rates for cancer are similar to elsewhere, age-standardised rates for mortality are higher and for survival are lower, particularly from cancers considered preventable (see note on age standardisation above). Tower Hamlets cancer strategy aims to reduce premature mortality from cancer and to reduce inequalities in cancer outcomes between Tower Hamlets and elsewhere, and within the borough.

The key interventions arising from Tower Hamlets cancer strategy are:

1. **Prevention and Public Awareness**
   - Support for Public Health campaigns to increase cancer awareness (such as the local ‘small c campaign’ and the national Be Clear on Cancer campaign)

2. **Early Diagnosis**
   - Endorsement of bowel screening in primary care
   - Use of the GP Cancer Decision Support Tool
   - Use of the RCGP Cancer Audit Tool

3. **Commissioning more effective Cancer Pathways**
   - ‘Straight-to-test’ for people referred with suspected gastro-intestinal cancer to avoid multiple appointments and reduce delays in diagnosis
   - Stratified follow-up for patients with prostate cancer, to reduce unnecessary outpatient visits and increase self-care, with primary care support

4. **Living with and Beyond Cancer**
   - Implementation of the Recovery Package consisting of Holistic Needs Assessment, Treatment summary, Cancer care review, Patient education and support

5. **Integrated Care**
   - Enhanced cancer care review in Primary care
   - Cancer as a long-term condition in the Integrated Care Programme

These interventions are monitored as part of Tower Hamlets Integrated Care Programme, reporting directly to the multi-agency Complex Adults Working Group in 2016/17.

WHAT IS CANCER?
There are more than 200 different types of cancer. The commonest cancers are of the lung, breast (in women), prostate (in men) and bowel (also called colorectal cancer). These four cancers account for more than half of all cancers diagnosed in this country and in Tower Hamlets.

Cancer starts when abnormal cells divide in an uncontrolled way. Some cancers may eventually spread into other tissues.

Mutations can happen by chance when a cell is dividing. They can also be caused by the processes inside the cell. Or they can be caused by things coming from outside the body, such as the
chemicals in tobacco smoke. Some people can inherit faults in particular genes that make them more likely to develop a cancer. Find out more at www.cancerresearchuk.org/about-cancer/.

5. WHAT IS THE LOCAL PICTURE?

Age and gender, and for some cancers, deprivation and ethnicity, are important fixed risk factors for cancer. Cancer incidence and mortality increase with age, for example, men aged 75 years or older are most likely to die from cancer than any other group. Knowing the demographic make-up of the local population is crucial to understanding the likely burden of cancer in an area.

INEQUALITIES

In England, inequalities in health exist between different population groups. Some may be related genetic differences, such as a higher prevalence of prostate cancer in black men and higher rates of liver cancer in some Asian populations\textsuperscript{11}. Others are more closely related to social and economic inequalities and linked to related behavioural and environmental factors, such as the high prevalence of lung cancer in the most deprived groups, related to higher smoking rates\textsuperscript{12}.

Inequalities also exist in people’s awareness of the signs of cancer and of available health services, and in perceived barriers to accessing services. This can affect how early cancer is detected, and subsequent health outcomes. London’s Five Year Cancer Commissioning Strategy 2014-2019 highlights evidence of low public awareness and understanding of screening programmes in some groups across the capital.

There are inequalities in patients’ experience of cancer care, with younger patients, people from minority ethnic groups, women and patients identifying as gay, lesbian or bisexual often reporting worse overall experience of care\textsuperscript{13}. Given the significant inequalities that exist across London, driven by factors including deprivation, ethnicity, single households and age, London’s Five Year Cancer Commissioning Strategy 2014-2019 recommends that specific locally driven interventions target local inequalities in access to services and outcomes of care.

PREVALENCE

Cancer prevalence is a count of people still alive who have been diagnosed with cancer in the past. The latest data shows that Tower Hamlets has the lowest prevalence rate in London at the end of 2013, with 2,038 patients per 100,000 population (London 3,346)\textsuperscript{14}. This represents 5,562 residents who were diagnosed with cancer since 1991. The prevalence rate reflects trends in cancer incidence, mortality and survival, as well as advances in cancer treatment and detection. The rate is not age standardised, and the young population profile in Tower Hamlets is a factor in relatively low prevalence of cancer, as are lower survival and higher mortality rates than London and England. The number of people living with and beyond cancer is increasing and is set to rise further, if existing trends continue\textsuperscript{15}.

INCIDENCE

Cancer incidence can be affected by the characteristics of a population. The age standardised cancer incidence rate per 100,000 people in Tower Hamlets (606.5) is similar than the England average rate of 615.3 (2012-2014) and the London rate of 593.6\textsuperscript{16}. Around 665 new cases of primary cancer are diagnosed in Tower Hamlets each year (figure 5).
SURVIVAL (1 YEAR) ALL AGES

One year survival is a good indicator of whether cancer is diagnosed early and whether people have rapid access to optimal treatment. The 1-year cancer survival rate in Tower Hamlets has increased over the past decade for all cancers combined. However it remains lower for cancers diagnosed in 2014 (65.7%) than the England average (70.4%) and has been consistently lower since 1999 (figure 1).

A series of reports analysing underlying factors in 1-year cancer survival for each of the London and West Essex CCGs identified a range of factors which may contribute to the lower rate in Tower Hamlets. These factors cover the National Awareness and Early Diagnosis Initiative (NAEDI) pathway and are grouped into three themes: public awareness, early diagnosis and treatment.

For the most common cancers, 1-year survival in Tower Hamlets has continued to increase for breast and lung cancer. However survival from bowel cancer has worsened and the rate was the lowest in England for people diagnosed in 2014 (65.3%; England 77.2%) (figure 2).

In depth analysis of the underlying factors shows lower rates for public awareness, screening uptake, access to investigations, referral rates and cancer waiting times compared to England average rates. Recommendations are to continue to introduce and evaluate interventions to increase earlier diagnosis and survival, including those which increase the uptake of bowel screening and extend screening through Bowel scope (see section on bowel screening).
The most recently published data shows that the age standardised mortality rate from cancer for people of all ages in Tower Hamlets between 2012-2014 was 606.5 per 100,000 population. This is not significantly worse than the rates for London (593.6) and England (615.3). Around 300 people die from cancer in Tower Hamlets each year (figure 5).

The cancer mortality rate for males in Tower Hamlets (365.5) is similar to the London (316.9) and England (338) rates. However the mortality rate for females (265.5) is the highest in London, and is significantly worse than the London (216.6) and England (231.5) rates.

Deaths from cancer before the age of 75 are considered premature. The under-75 mortality rate from cancer in Tower Hamlets improved to 150.9 in 2013-15, so that it is no longer significantly higher than the England rate of 138.8, although it remains higher than the London rate of 129.7 (Figure 3). The improvement is mainly due to a reduction in the rate for males since 2012. Around 156 people under the age of 75 die from cancer in Tower Hamlets each year (figure 5).
UNDER-75 CANCER DEATHS CONSIDERED PREVENTABLE

Deaths are considered preventable if all or most of them could potentially be avoided by public health interventions in the broadest sense. The under 75 mortality rate from cancer considered preventable in Tower Hamlets (92) is statistically similar to the England average rate of 81.1 (figure 4) although it remains higher than the London rate of 75.6\textsuperscript{27}. Since 2012, the Tower Hamlets rate appears to be improving at a faster rate than the rates for London and England, with a narrowing of the gap between them. This is reflected particularly in the rate for males. Around 95 people under 75 die from cancer considered preventable in Tower Hamlets each year (figure 5).

Figure 4. Trend in under-75 mortality rate from cancer considered preventable: 2001-15

![Trend in under-75 mortality rate from cancer considered preventable: 2001-15](image)

Figure 5. Incidence and mortality from cancer in Tower Hamlets

![Incidence and mortality from cancer in Tower Hamlets](image)

6. PREVENTION

Prevention is a major focus of both the London and national cancer strategies.

More than 4 in 10 cancer cases could be prevented by making changes such as not smoking, keeping a healthy body weight, cutting back on alcohol, maintaining a healthy diet and being physically active\textsuperscript{28}. Making these changes can also help to prevent recurrence of cancer, and to improve health and wellbeing for people living with and beyond cancer.

However, surveys of the population have shown that people aren’t necessarily aware that all of these things are linked to cancer. For example, the Cancer Research UK funded Perceptions of Risk
Survey found that only 3% of the people polled knew that being overweight or obese could increase their risk of cancer. 

Smoking is by far the most significant risk factor, responsible for 19% - or around 64,500 cases - of all new cancer cases per year in the UK. Both the London and national cancer strategies note that preventing cancer is not solely the responsibility of NHS organisations, but is a shared responsibility across local government, employers and the wider community.

WHAT ARE WE DOING TO PREVENT CANCER IN TOWER HAMLETS?

- A stop smoking service is free to all residents, and an enhanced Primary Care service enables additional support to be provided by GPs and pharmacists. In 2015/16, 1,484 adults were supported to stop smoking, achieving a higher quit rate than London and England averages.

- The Tower Hamlets Fit for Life service helps people with long term conditions to be more physically active and eat more healthily. This includes people living with and beyond cancer.

- Locally commissioned courses to teach English for Speakers of Other Languages (ESOL) with embedded health literacy content are provided across the borough, focusing on increasing awareness of cancer and access to prevention, screening and primary care services.

7. DETECTING CANCER EARLIER

When cancer is diagnosed at an early stage, treatment options and chances of a full recovery are greater.

For example, over 93% of bowel cancer patients diagnosed with the earliest stage of disease survive at least five years compared with less than 7% of those diagnosed with the most advanced stage disease. The same pattern is true for lung cancer, breast cancer, and for many cancers, common or rare.

However, detecting cancer earlier is a complex and cross-cutting challenge for both health professionals and the wider public. Inequalities exist, with some groups of patients more likely to be diagnosed with later stage disease.

The National Awareness and Early Diagnosis Initiative (NAEDI) notes that Public Health and the NHS both have a role to play in tackling late diagnosis and their progress will be measured through indicators in their Outcome Frameworks.

PROPORTION OF CANCERS DIAGNOSED AS EARLY STAGE

The proportion of cancers diagnosed at an early stage in NHS Tower Hamlets CCG in 2014 (35%) was lower than the England average (41%). A higher proportion of cancers in Tower Hamlets did not have stage recorded (33%) compared to the England average of 25%.

Early diagnosis of cancer (stage 1 and 2) gives patients more effective treatment options and improves their chances of surviving the disease. Reducing the number of patients diagnosed at a late stage (3 and 4) is crucial. Action along the diagnostic pathway is required to spot cancer early and treat it quickly.
Figure 6. The impact of earlier diagnosis of cancer

PUBLIC AWARENESS

Improving public awareness of the signs and symptoms of cancer and of available screening programmes has been identified as a priority for London.

Surveys conducted by Local Authorities and the NHS using the Cancer Awareness Measure in 2019/10 demonstrate evidence of wide variation of familiarity with the signs and symptoms of cancer, and low public awareness and understanding of screening programmes in some groups across London.

A lack of awareness of the signs and symptoms of cancer, along with barriers to presentation can delay diagnosis, leading to poorer patient outcomes.

Symptom awareness: % unprompted recall of a lump or swelling

The percentage of people in Tower Hamlets who, unprompted, recalled a lump or swelling as a possible symptom of cancer (42%) is lower than the England average (68%).

Barriers to diagnosis

The proportion of people in Tower Hamlets who reported having difficulty in getting a GP appointment (43%) is similar to the England average (42%).

The proportion of people in Tower Hamlets who reported feeling worried about what the GP might find as a barrier to visiting their GP (37%) is similar to the England average (37%).

Research suggests that people in England are significantly more worried or embarrassed than those in other countries about seeing their doctor with a symptom that might be serious. Reducing these barriers is important in improving earlier diagnosis.

SCREENING

Cancer screening is important in the early detection of cancer.

The three national cancer screening programmes are based on internationally recognised principles of screening. Screening identifies individuals who may be at higher risk of a disease or condition amongst large populations of healthy people. Once identified, those individuals can consider further tests, and healthcare providers can offer them interventions of benefit. A screening programme needs to offer more benefit than harm, at a reasonable cost to the NHS.
The cancer screening strategy for London identifies the need to (i) increase public awareness of screening, (ii) increase engagement with primary care and improve reliability of data, (iii) improve quality, capacity and patient experience of provider services to optimise coverage and uptake and (iv) to facilitate high quality research to further inform strategies to improve coverage and uptake in London.

CERVICAL SCREENING WOMEN FOR AGED 25-64 YEARS

Cervical cancer screening detects changes in cells that may become cancer, so that they can be removed and cancer prevented. Screening is estimated to save 4,500 lives in England each year.

The national coverage target for cervical screening is 80%. Coverage in NHS Tower Hamlets CCG in 2015-16 was 63.7%, similar to the London average of 66.8% and lower than the England average of 72.8%. Tower Hamlets rate has declined since 2013 (figure 7).

Figure 7. Cervical screening coverage in Tower Hamlets, women aged 25 – 64: 2009 to 2016

The rate is particularly low nationally and locally for younger women aged 25 to 49. In Tower Hamlets 61% of younger women were screened (London 63.7%, England 70.2%)36.

BOWEL SCREENING FOR MEN AND WOMEN AGED 60-74 YEARS

Bowel screening aims to prevent cancer developing by detecting and removing abnormal cells (polyps) which may become cancer over time. It is also the best way to spot bowel cancer earlier. More than 9 out of 10 people with bowel cancer survive if it is diagnosed at an earlier stage.

The national target for uptake of bowel screening is 60%. A coverage target has not been published. The Bowel screening coverage rate in NHS Tower Hamlets CCG in 2015/16 was 41.2%, lower than the rate for London (49%) and for England (58.5%) (figure 8)37.
Bowel scope screening is a new one-off test being offered to men and women at the age of 55. It is being rolled out gradually across England by the NHS Cancer Screening Programme. The test uses a thin, flexible tube with a tiny camera on the end to look at the large bowel. It can find and remove small growths called polyps from the bowel, and prevent bowel cancer from developing. There is evidence that for every 300 people screened, it stops two from getting bowel cancer and saves one life from bowel cancer. It is expected that Bowel scope will be offered in Tower Hamlets from 2018.

**BREAST SCREENING FOR WOMEN AGED 53-70 YEARS**

Breast screening can identify cancer before symptoms are noticed. It is one of the best ways to spot breast cancer earlier. Women are more likely to survive breast cancer if it is diagnosed at an earlier stage. The national minimum standard for coverage of women aged 53 to 70 is 70% and the national target is 80%.

Breast screening coverage (53-70 years) in Tower Hamlets Local Authority area (62.5%) is lower than the London rate of 69.2% and the England average of 75.5% (figure 9).
REFERRAL AND DIAGNOSIS
Urgent referral pathways (such as the two week wait for a diagnostic test) are linked with reduced mortality. However, only 30% of cancers are diagnosed through this route\textsuperscript{39}. The proportion of patients referred through the urgent pathway who are subsequently diagnosed with cancer is around 10%, and this group have increased survival rates.

Recently published NICE Guidelines on GP referral for suspected cancer\textsuperscript{40} contain guidance which aims to reduce pathways associated with worse outcomes, such as emergency presentation, by reducing the ‘threshold of risk’ for referring patients with suspected cancer through the two week wait referral pathway.

EMERGENCY PRESENTATION

The proportion of patients diagnosed with cancer through emergency routes in NHS Tower Hamlets CCG (26%) is higher than the England average (20%)\textsuperscript{41}.

Higher numbers of patients diagnosed through emergency routes may indicate late diagnosis. Emergency presentations have a significantly reduced 1 year survival.

62 DAY WAITING TIMES FOR TREATMENT

The percentage of cancer patients who received their first treatment within 62 days of an urgent GP referral for suspected cancer in Tower Hamlets in 2015/16 (81.8%) was similar to the England average (81.3%) but did not meet the operational target of 85%\textsuperscript{42}.

The speed that patients receive their first treatment can have a positive impact on their likely clinical outcome, can help to reduce anxiety and contribute to a better patient experience.

SAW GP ONCE/TWICE BEFORE BEING TOLD THEY HAD TO GO TO HOSPITAL

The percentage of patients who reported seeing their GP only once or twice before being told they had to go to hospital in Tower Hamlets (68%) was lower than the average for England in 2015 (76%)\textsuperscript{43}.

Reducing the number of times that patients see their GP with a cancer symptom before they see a specialist improves early diagnosis, minimises the stress of uncertainty, and frees up GP time.

WHAT ARE WE DOING TO DIAGNOSE CANCER EARLIER IN TOWER HAMLETS?
(i) Increasing public awareness of cancer
- From 2011 to 2016, local community organisations were commissioned to talk to around 4,000 residents a year, targeting those at highest risk of late diagnosis of cancer. When asked at least a month later, people who had been engaged showed increased awareness of symptoms and reduced barriers to seeing a doctor if they noticed a warning sign of cancer.

(ii) Increasing screening uptake
- A Primary Care enhanced service between 2014 and 2016 enabled GP practices to support people to take up bowel screening through endorsement and extra information. Bowel
screening coverage increased by 8.3% to 41.2% in March 2016, a greater increase than elsewhere in London.

- Since September 2015, NHS England has commissioned a service to work with GPs calling women who did not attend their breast screening appointments, to endorse and explain screening and to make new appointments for them. This is in response to a decline in screening coverage in 2013-14, reversing increases in previous years.

- More work with NHSE commissioners and primary care is needed to increase participation in screening.

(iii) Supporting for GPs to diagnose cancer earlier
- A Primary Care Enhanced service is in place to implement evidence based interventions to improve referrals of people with suspected cancer. This includes using and evaluating the cancer decision support tool, and reviewing and learning from pathways of people diagnosed with cancer using audit and significant event analysis.

- A Cancer Research UK Primary Care Engagement Facilitator provides support and capacity for GP practices to use the enhanced service to implement earlier diagnosis interventions

(iv) Improving diagnostic pathways
- Primary and secondary care are working together to improve access to investigations for gastrointestinal and lung cancer through direct access by primary care and “straight-to-test” referral to secondary care (investigations ahead of hospital consultation to speed up diagnosis).

- The main local provider of cancer services is commissioned in line with best practice guidelines for the early detection of bowel, lung, ovarian cancer, with a current focus on implementing a faster pathway for lung cancer referrals.

8. TREATMENT
Treatment for cancer is most often comprised of a combination of chemotherapy, radiotherapy or surgery, or all three. In certain cases it can involve hormone treatment or biological therapies.

It is estimated that 4 in $10^{14}$ cancers are cured due to radiotherapy and 5 in $10^{15}$ due to surgery.

Treatments are provided alongside social and psychological support as well as rehabilitation during and following treatment. The Cancer Strategy for England 2015-2020 states that “patients should have access to the best evidence-based treatments available [which] will mean reducing variation across the country, upgrading radiotherapy technology, and using medicines in more stratified ways”.

The case for change in London noted that variation in practice across the city is leading to variation in the quality of services offered to patients, and ultimately to care outcomes. Cancer Alliances aim to address variation by better coordination of resources and services.

There is limited local level data of comparable quality to gain a complete understanding of cancer treatment. Data at Trust level from the national lung and colorectal cancer audits has been used in this analysis.
TREATMENT FOR NON-SMALL CELL LUNG CANCER

The proportion of patients with non-small cell lung cancer treated at Barts Health NHS Trust who received anticancer treatment in 2014-15 was 63.5%, higher than the audit average (England and Wales) of 60%. The proportion of this group that received curative surgery was 17.5%, exceeding the audit average of 16.7%.

Anticancer treatment refers to therapies (surgery, radiotherapy, chemotherapy) against the cancer itself, rather than just against the symptoms. Patients with lung cancer are often older and have other comorbidities, which can sometimes make treatments challenging, but delivering more anticancer treatment to patients is necessary to achieve the goal of improving quality of life and survival.

Variation exists between Trusts in the proportion of patients who receive treatment and in particular, curative surgery. Some of this variation is due to “case mix” with higher numbers of patients in some areas who are not fit for surgery e.g. because of other serious long term conditions.

90 DAY POST-OPERATIVE MORTALITY FOR COLORECTAL CANCER PATIENTS

The adjusted 90-day post-operative mortality rate for colorectal cancer patients diagnosed in 2014-2015 at Barts Health NHS Trust was 3.7%, similar to the England average of 3.8%.

Post-operative mortality is an indicator of patient selection and postoperative care employed by multidisciplinary teams. While post-operative survival is at an all-time high, variation remains

PATIENTS’ OVERALL RATING OF THEIR CARE

Using a scale of zero (very poor) to 10 (very good), the adjusted score for people with cancer in Tower Hamlets was 8.5, similar to the England average of 8.7.

Patient experience is generally rated lower in London than elsewhere in England. Ensuring that patients experience good quality, compassionate care is a key part of the cancer journey.

WHEN TOLD THEY HAD CANCER, PATIENTS COMPLETELY UNDERSTOOD THE EXPLANATION AND WERE GIVEN EASY TO UNDERSTAND WRITTEN INFORMATION

77% of respondents in Tower Hamlets said they completely understood the explanation of what was wrong, similar to the national average of 72%.

72% of respondents said they were given easy to understand written information about the type of cancer that they had, the same score as the national average of 72%.

All cancer patients should be provided with the information they need to understand their disease and to participate fully in shared decisions about their care. Offering patients easy to understand
written information about their cancer when they are diagnosed is important in supporting them at what can be a confusing and difficult time.

### SUPPORT FROM HEALTH OR SOCIAL SERVICES DURING TREATMENT

The percentage of Tower Hamlets cancer patients who reported definitely receiving enough support from health or social services during treatment (52%) is similar to the England rate of 54%.

Almost half of patients in Tower Hamlets and in England do not feel that they receive enough support from services during their treatment.

### BEING TREATED WITH RESPECT AND DIGNITY BY HOSPITAL STAFF

The percentage of Tower Hamlets patients who reported always being treated with dignity and respect by hospital staff (74%) is significantly lower than the England rate of 87%.

London’s 5-year cancer strategy notes that issues around staff behaviour, and compassionate and respectful care are often mentioned in hospital complaints. Learning from good practice, and celebrating success where things have worked well, will be vital in improving experiences.

### BEING INVOLVED IN DECISIONS ABOUT CARE AND TREATMENT

The percentage of Tower Hamlets patients who reported that they were definitely involved in decisions about their treatment (79%) is similar to the rate for England (78%).

Patient centred care is at the heart of healthcare. London’s 5-year cancer strategy and the national cancer strategy asks providers to ensure that the patient perspective is understood and is part of all decisions about care.

### HOSPITAL AND COMMUNITY STAFF ALWAYS WORKED WELL TOGETHER

The percentage of patients in Tower Hamlets who reported hospital and community staff always worked well together (59%) is similar than the England average of 61%.

Transferring between settings of care or between teams is known to cause challenges for patients, as they potentially get stuck or lost in the system, or have to repeat their medical history and routine tests. Integration between settings of care helps to improve transitions. Around 40% of cancer patients in England do not feel that the services they receive are always integrated.

### BEING GIVEN THE NAME OF A CLINICAL NURSE SPECIALIST TO PROVIDE SUPPORT

The percentage of Tower Hamlets patients who reported that they were given the name of the Clinical Nurse Specialist (CNS) who would support them through their treatment (84%) is significantly lower than the England average of 90%.
According to the Cancer Patient Experience Survey, having access to a CNS has the greatest positive impact on overall experience of care, and is linked to positive clinical outcomes.

WHAT ARE WE DOING TO IMPROVE TREATMENT OF CANCER IN TOWER HAMLLETS?

Barts Health NHS Trust, the main provider of cancer services is commissioned and supported

- to use the best practice diagnostic and treatment pathways in order to reduce variation and inequalities in outcomes, and to improve overall quality
- to reach Improving Outcomes Guidance (IOG) compliance through effective performance management of contracts and using results of the National Cancer Peer Review

9. LIVING WITH AND BEYOND CANCER

A person is living with and beyond cancer once they have received a diagnosis of cancer. This could be someone who is having treatment or has completed their treatment for the cancer.

There are two million people living with or beyond cancer in the UK and this number is calculated to rise to four million by 2030\(^5\). In Tower Hamlets, 3,600 adults with a diagnosis of cancer were on GP registers in April 2016. Almost three quarters (72%) have at least one other long term condition.

People living with and beyond cancer have broad and diverse needs, many of which are not fully understood. One in four people who has been treated for cancer, lives with ill health or disability as a consequence of their treatment\(^50\).

Better support for people and their carers during and after treatment can deliver significant benefits in terms of improved quality of life. It can also encourage behaviours that are more likely to improve recovery during treatment, prevent recurrence or acute presentations back to the health service with late consequences of treatment. The National Independent Taskforce report called on the NHS and partners to “drive forward a programme of work to ensure that people living with and beyond cancer are fully supported and their needs are met which should include approaches to reducing and managing long-term consequences of treatment”\(^51\).

The Model of Care for London recommends that follow-up and aftercare services are reviewed and, where necessary or desirable, replaced with bespoke aftercare services based on the vision of the National Cancer Survivorship Initiative (NCSI), which seeks to ensure better support for survivors, and their carers beyond hospital treatment\(^52\).

BEING TOLD ABOUT SIDE EFFECTS THAT COULD AFFECT THEM IN THE FUTURE

The percentage of Tower Hamlets patients who reported hospital staff definitely gave them information about the side effects of treatment that could affect them in the future was 53%, similar to the England average of 54%.

A significant proportion of people with cancer experience a wide range of distressing medium and long-term problems, such as anxiety and depression, bowel and urinary incontinence, crippling fatigue, pain or sexual difficulties. Some have increased risk of heart or bone problems, a second cancer, or other health conditions that may not emerge for decades.
People with cancer are 1.4 times more likely to be unemployed than the general population and many struggle with little or no coordinated support to remain in work following treatment.

Almost half of all patients in Tower Hamlets (and in England) do not feel that they were given enough information about how cancer could affect them in the future.

**INFORMATION ABOUT HOW TO GET FINANCIAL HELP**

The percentage of Tower Hamlets patients who reported that hospital staff gave them information about how to get financial help they might be entitled to (53%) is similar to the England average of 55%.

4 in 5 cancer patients have average costs of £570 a month as a result of their illness through loss of income and additional costs of their illness. (A third lose £860 a month because they are unable to work or have to cut down their hours. 6 in 7 have increased monthly expenses of £270).

Almost half of patients in Tower Hamlets (and in England) report not being given information about getting financial help by hospital staff.

**BEING GIVEN A CARE PLAN**

The percentage of Tower Hamlets patients who were given a care plan was 31%, similar to the England average of 33%.

London’s 5-year cancer strategy and the national cancer taskforce strategy state that every person with cancer will have access to the elements of the recovery package, including a holistic needs assessment and a written care plan. Although this is an improvement on previous years, more than two thirds of patients in Tower Hamlets (and in England) said they did not receive a care plan.

**BEING GIVEN CLEAR WRITTEN INFORMATION ABOUT WHAT THEY SHOULD OR SHOULD NOT DO AFTER LEAVING HOSPITAL**

The percentage of patients who reported being given clear written information about what they should or should not do after leaving hospital in Tower Hamlets (85%) is similar to the England average (84%)

London’s 5 year cancer strategy and the national cancer taskforce strategy state that every person with cancer will have access to the elements of the recovery package, including a Treatment Summary at the end of active treatment. Providing clear written information on leaving hospital is also linked to improved patient experience and a reduction in unplanned readmission.

**WHAT ARE WE DOING IN TOWER HAMLETS TO SUPPORT PEOPLE LIVING WITH AND BEYOND CANCER?**

1. Barts Health NHS Trust, the main provider of cancer services is commissioned to ensure that these elements of the Macmillan Recovery Package are implemented
• undertake holistic needs assessments (HNA) jointly with patients at the point of diagnosis and at other key transition points along the patient pathway; and that a record of the assessment including a care plan is shared with the patient and GP with patient consent. The care plan is updated each time an HNA is conducted.

• provide Treatment Summaries to all patients and their GPs at the end of active treatment.

• invite patients to Health and Wellbeing events in the community or hospital to help to prepare people for the transition to supported self-management. These should include: advice on healthy lifestyle and physical activity, signposting to relevant services including rehabilitation, work and financial support services, signs and symptoms to look out for regarding recurrence of their cancer.

The threshold for performance for each of these elements of the recovery package is 70%. In 2015/16, most London Trusts had not yet achieved the threshold. Recording by Barts Health NHS Trust estimates that less than 10% of patients received each of these elements.

2. Barts Health NHS Trust is commissioned to implement stratified follow-up pathways of care, starting with patients treated for breast, prostate and colorectal cancer. This means that all patients are assessed for their degree of self-efficacy and supported self-management or specialist follow-up is planned accordingly.

In 2015/16, the threshold for performance for breast cancer patients on stratified pathways was 70%, and for prostate and colorectal cancer patients was 40%. In 2015/16, most London Trusts had not yet achieved these thresholds. Recording by Barts Health NHS Trust estimates that less than 25% of breast cancer patients were on a stratified pathway.

3. As part of the Tower Hamlets Integrated Care Programme people with cancer

• are included in the Tower Hamlets Integrated Care Programme (ICP) according to their needs. In 2015, 2,700/89% of people living with and beyond cancer were within the 20% of the population at highest risk of unplanned hospital admission, and were included in the ICP.

• receive holistic cancer care reviews in primary care. During 2016/17, as part of the Integrated Care service in Primary Care, GPs offered enhanced cancer care reviews for their patients within 6 months of diagnosis.

• have their care integrated with other long term conditions management, in line with NICE guidance on the management of multi-morbidity.

• are offered psychological support both during active treatment and afterwards; more information is needed about how well this is provided in Tower Hamlets.
4. Services that offer support to people in living with and beyond cancer in Tower Hamlets include
   - Rehabilitation services such as Accelerate CIC (management of lymphoedema), Barts Cancer Transitions Programme, Prostate Cancer Rehabilitation service, Ability Bow (for people with disabilities to be more active)
   - Macmillan Social Prescribing service which assists people with cancer to access a range of activities to increase their health and wellbeing
   - Macmillan benefits advice service at the main hospital sites across East London and in the community at Toynbee Hall

5. In 2017, Tower Hamlets council formed a partnership with Macmillan Cancer Support as one of 6 pilots working with Local Authorities in the UK. The ‘Living with Cancer Programme’ aims to develop and pilot an integrated model of care to meet the needs of people living with and beyond cancer.

This is in response to Macmillan’s research which shows that as survival from cancer improves, the number of people living with cancer as a long term condition is increasing, with evidence that the psychosocial needs of people with cancer are not always met.57

10. END OF LIFE CARE
End of life care aims to help people live as well as possible and to die with dignity. It also refers to care during this time and can include additional support, such as psychological support or help with legal matters.

Forty-three per cent of the 400,000 people each year that have a palliative care need will have cancer, and this number will grow as cancer incidence increases.58

The Model of Care44 advises that providing holistic and integrated supportive and palliative care are essential to improving patients’ experiences of services, enabling self-care and improving patients’ quality of life, and recommends that current NICE Guidance59 on supportive and palliative care is implemented across London.

PLACE OF DEATH
Most people when asked would prefer to be cared for and to die in their own home and few people say they would wish to die in hospital. Surveys show that the quality of care is often rated less well for people who die in hospital. The proportion of deaths which occur in “usual residence” is therefore used as a quality measure, indicating person centred care at the end of life.

In recent years, the proportion of people who die in their ‘usual residence’ has been increasing, and the proportion of people that die in hospital has been declining. London as a whole has a higher proportion of people who die in hospital (53%, 2015) compared to the England average rate (47%); and a lower rate of people who die in their usual residence (38%; England 46%). This is reflected in Tower Hamlets where 55% of deaths occur in hospital and 31.5% in ‘usual residence.’ A higher rate of deaths occur in a hospice in Tower Hamlets (10%) compared to England (5.6%; London 6.5%).

For people with cancer, the rate of death in ‘usual residence’ is significantly lower than the England rate (24.7%; London 35.3%; England 44.4%).
SPECIALIST PALLIATIVE CARE SERVICES
A high proportion of patients with cancer receive specialist palliative care compared to patients with other diagnoses, yet there is limited comparable local data to help understand the effectiveness of these services. The collection and availability of such data should be reviewed.

BEREAVED CARERS VIEWS ON THE QUALITY OF CARE
Each year in England, a sample of bereaved carers of adults who died in the last year are asked about the quality of care in the last 3 months of life. The survey aims to assess variations in the quality of care delivered in different parts of the country and to different groups of patients.

The most recent survey found that for people who died from cancer, overall quality of care in the last 3 months was rated as outstanding or excellent, significantly higher than care for people dying from cardiovascular disease or other causes. Just under half (47%) of cancer patients had care rated as outstanding or excellent, compared with 38% of cardiovascular patients and 41% of people dying from other causes.

The sample size at local level is considered too small for comparison. Data from the combined years 2011 and 2012 was last used to report at local level.

OVERALL, AND TAKING ALL SERVICES INTO ACCOUNT, HOW WAS THE PATIENT’S CARE RATED IN THE LAST THREE MONTHS OF LIFE

The percentage of carers who reported care in the last three months of life as being outstanding or excellent in NHS Tower Hamlets CCG (31% ) was lower than the best in England (56%, South Devon and Torbay) and the average for England of 43%.

There is more on end of life care in the Tower Hamlets Last Years of Life Joint Strategic Needs Assessment (JSNA).

WHAT ARE WE DOING TO IMPROVE THE EXPERIENCE FOR PEOPLE WITH CANCER AT THE END OF LIFE IN TOWER HAMLETS?
Tower Hamlets Integrated Care Programme aims to provide person-centred care to people with complex care needs, including those in their last years of life. Key functions are to ensure that:

- health and social care staff support people to express their preferences about their care and place of death
- peoples’ preferences about their care and key details are recorded and with consent, shared appropriately
- Specialist Palliative Care services are provided in community, hospital and hospice settings; this includes support for families and carers, including bereavement care
- comprehensive multi-agency training to improve the skills and confidence of all those supporting people in the last years of life is provided through a Foundations in Palliative Care education programme
- the views of bereaved carers are sought and used to help improve services to support people and their families and carers in the last years of life
11. CONCLUSION

Interventions in line with the national and local strategies are in place or planned in Tower Hamlets. These aim to reduce the incidence of preventable cancers; to increase survival and to reduce mortality from cancer; and to improve the health and wellbeing of people affected by cancer, including meeting their psychosocial needs.

The Tower Hamlets Integrated Care Programme oversees the implementation of these interventions, and makes recommendations to further improve outcomes and to reduce in equalities in outcomes from cancer for the local population.

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National Cancer Patient Experience Survey 2015 http://www.ncpes.co.uk/


http://www.hscic.gov.uk/lung

The 90 day post-operative rate mortality after major surgery for colorectal cancer patients diagnosed in 2014-2015 http://www.hscic.gov.uk/bowel


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54 Transforming Cancer Services for London Dec 2016 Living with and Beyond Cancer: a long term condition

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