Cancer services
Case for change

March 2010
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Foreword

In London each year, more than 13,000 people die from cancer, with more than half of them under the age of 75. Good progress in caring for cancer patients has been made in the last decade, but more needs to be done to ensure the capital’s cancer services become among the very best in the world.

London is a world-class city and Londoners deserve a world-class healthcare system. Ensuring high quality care for people with cancer has been a focal point for the NHS for some years. The Department of Health’s *NHS Cancer Plan* (2000), the *Cancer Reform Strategy* (2007) and Professor the Lord Darzi’s, *Healthcare for London: A Framework for Action* (2007), highlighted the need for reform. There are inequalities in cancer outcomes in London, and the quality and safety of patient care could, and should, be better.

We recognise London’s challenges of the need to diagnose people with cancer earlier; transforming patient care for the better, and tackling inequalities in order to achieve a world-class cancer service. The cancer project is clinically-led and supported by experts with a wide range of clinical experience and considerable expertise drawn from within and outside London.

The NHS in London must provide all patients with cancer services that effectively use resources to deliver the best health outcomes. This case for change will assist London’s healthcare professionals to clarify where services need to change.

“The overwhelming message in the case for change is that maintaining the status quo is not good enough. To provide world-class services across the whole of London, and to address the existing inequalities between London PCTs, requires radical change. The case for change, and its call for action to develop new service delivery models, has my full support”.

Professor Sir Mike Richards CBE, National Cancer Director

We most sincerely thank the many individuals and organisations that helped to develop the case for changing London’s cancer services on behalf of London’s PCTs, including primary and secondary care professionals, service users, and statutory, independent and third sector partners.

Bill Gillespie  
Chief Executive, Sutton and Merton Primary Care Trust and Senior Responsible Officer, Healthcare for London Cancer Project

Professor John Toy  
Professor of Cancer Medicine at Queen Mary, University of London and Clinical Lead, Healthcare for London Cancer Project
1. Introduction

It is estimated that one in three people will be diagnosed with cancer at some point in their life\(^1\) with incidence projected to rise.

Around 13,600 people die from cancer in London each year, with more than half of them under 75 years of age. The number of new cancer cases in London is predicted to increase from around 27,000 in 2002 to 28,500 in 2022.\(^2\)

Cancer care in the UK has improved over the last decade. Cancer networks have been instrumental in this but there are areas that need further improvement to ensure London’s cancer services are among the best in the world. If the UK’s cancer survival equalled Europe’s best, there would be an estimated 11,000 fewer deaths each year.\(^3\) This would mean saving roughly 1,000 Londoners’ lives per year.

The scope of the Commissioning Support for London cancer project was determined in consultation with the Department of Health’s national clinical director, NHS London’s medical director and key stakeholders, including representatives from primary care trusts (PCTs) and sectors.\(^4\) The project focuses on three areas of work:

1. Early diagnosis.
2. Common cancers and general care.
3. Rarer cancers and specialist care.

This document presents the case for change, for each area of work, in the framework of national policy, changing cancer epidemiology and current service provision. It brings together national, pan-London and local information, considers services across patient pathways and provides a critique of current cancer services in London.

An expert group drawn from a range of clinical specialities, hospitals, and cancer networks helped develop this case for change. Their role was to represent the views and expertise of their peers, who deliver cancer-related services across the capital. A patient and carers panel was also established to input into the project.

The outcomes of this project will feed into acute reconfiguration plans being developed by London’s six commissioning sectors, as part of a system-level change programme to ensure the capital is in the best position to address healthcare challenges of the future.

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\(^1\) Office for National Statistics, Cancer incidence, mortality and survival, 2005,


\(^3\) Cancer Research UK, Tackling cancer delays will boost British survival, November 2008
[accessed September 2009]

\(^4\) The following aspects of the patient pathway are outside the scope of this review: Prevention, paediatric cancer services and end of life care
2. The national and local context

2.1 Policy overview

The delivery of high quality cancer care has been an area of focus in the UK for the last 15 years. The Calman Hine report highlighted that outcomes for UK cancer patients were worse than most other European countries.\(^5\) Reasons for this included poor communication between professionals in different care settings, and inadequate planning and coordination of care between specialists. The report proposed the establishment of networks, stressed the importance of multidisciplinary consultations and management, and recognised the importance of collecting high quality, comprehensive cancer registration data.

With the subsequent publication of the *NHS Cancer Plan*\(^6\) in 2000, the Government set out its vision to improve cancer services to become, and stay, comparable with other European countries, with a programme of investment and service improvement. Significant resources were allocated to improving standards and reducing waiting times.

Following the progress made since the *NHS Cancer Plan*, the Department of Health published the *Cancer Reform Strategy*\(^7\) in 2007, setting out a programme of action to ensure cancer services in England are among the best in the world by 2012. The strategy acknowledged that national guidance would play a vital role as cancer services developed and was effectively the strategic plan used by the London cancer networks.

The strategy identified that England uses more hospital beds for cancer than other countries, which accounted for a large proportion of total cancer expenditure (see figure 1).

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\(^7\) Department of Health, *Cancer Reform Strategy*, 2007
The Department of Health’s national clinical director for cancer subsequently set the goal of reducing cancer bed days by 20%, improving quality of care for patients, and reducing the cost of cancer care\(^8\) – saving around one million bed days per year in England and around 100,000 in London. In London we need to focus on enhancing services that improve patient outcomes and decrease spending in areas that do not, such as unnecessary bed days.

It is estimated that more than £3.6bn is spent on cancer care in secondary care and tertiary care across England (excluding screening costs). In London it is estimated that cancer care in hospitals costs London PCTs in excess of £0.5bn. This cost is broken down in figure 2.

\(^8\) Department of Health, *Cancer Reform Strategy*, 2007
Figure 2 represents approximately 11% of London PCTs’ expenditure on acute services. It is estimated that each PCT’s breast screening costs amount to about £0.5 million; that totals £15 million for London. See appendix 1 for a more detailed breakdown of the cost of cancer services in London.

A key message in the Cancer Reform Strategy is achieving world-class commissioning by setting the role of network teams as a commissioning resource to PCTs. The National Cancer Action Team (NCAT) has developed a cancer commissioning toolkit to support PCTs, working collectively in their cancer networks, to implement the Cancer Reform Strategy. In London, directors of cancer networks have driven this work and progress is being made. To achieve world-class cancer services, commissioning needs to be collaborative and based on patient care pathways with input from cancer clinicians.

“It is clear that future NHS funding will not match previous increases and this may result in increasing discordance between available resource and cost to deliver state of the art cancer care. To manage this properly a strategic pan-London approach is vital to maximise efficiencies and reduce costs of duplicate services.”

Consultant haematologist

Key message

The best health outcomes are achievable by expert and objective commissioning support, with input from cancer clinicians and patients, and based on patient care pathways.

2.2 National trends – incidence and mortality

Progress has been made in improving cancer outcomes in the UK to meet those of other developed countries. Deaths from cancer in the UK fell from 1993 and 2004 for both men (15%) and women (11%) but the UK still has a comparatively high mortality rate. For example, despite a 28% reduction in breast cancer mortality between 1992 and 2005, the UK has the highest breast cancer mortality rate compared with other developed countries. In 2001 and 2002 women in the UK had mortality rates higher than the European average for ovarian cancer (third highest) and bladder cancer (highest among reporting countries).

Figure 3 illustrates the UK’s performance for all cancers compared with other developed countries. Mortality and incidence trends for all cancers show the combined effect of varying rates of different cancer types. Known variability in completeness of cancer registrations in different countries makes exact comparisons between countries

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difficult to impossible. Plans to undertake more detailed work on a smaller set of countries with good registry data (including the UK) will enable observation of comparative trends for individual tumour types.\textsuperscript{11}

If UK cancer survival rates equalled the European average, there would be 6,500 fewer deaths per year.\textsuperscript{12} If UK survival rates equalled the best in Europe, this would equate to around 11,000 each year. In the 1980s, there were an estimated 12,000 avoidable deaths each year.\textsuperscript{13} Although the UK has saved the lives of around 1,000 people with cancer, there remains a huge amount to do.

Over the next 20 years, the cancer burden will increase. Cancer incidence, prevalence and mortality will variably change due to:\textsuperscript{14}

- Population increase.
- Changing demographics. Cancer incidence rises with increasing age. By 2031 it is projected that over 40\% of the total UK population will be aged 50 and over. The

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure3.png}
\caption{Age standardised cause of death from malignant neoplasms in comparable developed countries in Europe and the world, 1993-2004}
\end{figure}

\textsuperscript{11} Wilkinson E, ‘Questions remain over validity of EUROCARE data’, \textit{The Lancet}, 2009
\textsuperscript{12} Cancer Research UK, \textit{Tackling cancer delays will boost British survival}, op. cit
\textsuperscript{13} Cancer Research UK, \textit{Tackling cancer delays will boost British survival}, op. cit
\textsuperscript{14} South West London Cancer Network, \textit{Collaborative Commissioning Initiative}, 2007
nation’s older population is currently growing twice as fast as the population as a whole.\textsuperscript{15}

- Public health interventions, such as prevention (including human papilloma virus (HPV) vaccination) and early detection campaigns.
- Advances in treatment technologies leading to higher survival rates.
- Reduced exposure to various cancer-inducing risk factors.
- Lifestyle choices, for example, smoking, obesity and alcohol consumption.

Figure 4 shows trends in cancer incidence and mortality in the UK between 1975 and 2007.

\begin{center}
\textbf{Figure 4: Age standardised (European) incidence rates for all cancers (excluding non-melanoma skin cancer) and mortality rates for all cancers, Great Britain, 1975 - 2007}
\end{center}

Cancer incidence is predicted to increase nationally by around a third overall between 2001 and 2020.\textsuperscript{16} In terms of NHS investment, cancer is already the third largest disease specific programme. Costs are expected to rise due to increasing volume of interactions (due to both an increasing incidence and higher survival rates, with the latter leading to an increase of monitoring and treating recurrences); changes in healthcare delivery (for example, expansion of screening programmes); and the emergence of new and often costly treatments.

\textsuperscript{15} South West London Cancer Network, \textit{Collaborative Commissioning Initiative}, 2007
2.3 **London challenges**

The challenges and characteristics specific to London, in terms of population demographics and cancer services provision, are presented below.

2.3.1 **Patient experience**

Londoners have historically reported a poorer experience of cancer care when compared with other regions of England. In a 2004 National Audit Office survey,\(^\text{17}\) patients from London gave less positive responses than those from other regions. Differences were particularly noticeable in answers relating to community and hospital services, and the interface between them. The study strongly indicated that London cancer patients had poorer experiences regardless of cancer type, gender and age. Although London patients recorded a poorer experience of care, the preceding National Audit Office report\(^\text{18}\) did not show the capital’s cancer patients had worse survival and mortality rates than other parts of England.

A more recent survey of north London cancer patients\(^\text{19}\) found that a less positive experience of care was reported in primary care services. Of these patients, 31% thought they waited too long to be seen by a specialist and 23% felt that their condition worsened while doing so. Two-thirds of patients (65%) could not remember being offered a choice of hospital for their first hospital appointment and around half of all outpatients did not receive copies of letters sent from their hospital doctor to their GP.

**Key message**

Londoners have historically reported a poorer experience of cancer care when compared with other regions of England.

2.3.2 **Demographics**

London has a young and often transient population, which has a potential impact on the ongoing management of cancer. There are high rates of chronic illness among Londoners, leading to many more cancer patients having co-morbidities affecting their outcomes and experience of the health system. There is a higher proportion of single person households compared with the rest of the UK and this has negative implications for inpatient discharge and aftercare. These characteristics make the

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\(^{17}\) National Audit Office, *Tackling Cancer: Improving the Patient Journey*, 2005


\(^{19}\) Picker Institute Europe, *North London Cancer Network Patient Survey*, 2009
need for a planned and coordinated system for delivering London’s cancer services all the more important.

2.3.3 Inequalities in outcomes

"London has particular challenges with a very ethnically diverse and mobile population. [There are] areas of extreme wealth intermingled with extreme deprivation. Education and awareness may be a particular concern in areas of socio-economic deprivation."

Consultant haematologist

There is significant variation in the incidence and mortality rates of cancer patients in London PCTs. For example, between 2003 and 2005, the incidence of cancer in Tower Hamlets residents was 430 (per 100,000 age standardised population) compared with 301 in Redbridge, as shown in figure 5.

![Figure 5: Incidence of all malignant neoplasms in all London boroughs, 2003-2005](image)

Source: National Cancer eAtlas and HNAT for Tower Hamlets and City of London.

Between 2003 and 2005, Tower Hamlets had the highest mortality rate in London for all cancers at 220 (per 100,000 of the age standardised population), compared with
the lowest rate of 130 per 100,000 age standardised population in Kensington and Chelsea as shown in figure 6.

Incidence and patient survival rates for many cancers are known to relate to socio-economic status. The risk of being diagnosed with certain cancers is greater among the most deprived families and communities and, for the majority of cancers, the most deprived patients have worse survival rates. The incidence of some cancers varies between different ethnic groups. Some cancers may be due to lifestyle factors and others may be due to genetic factors.

Survival rates for most types of cancer have risen steadily since the 1970s. Rates have increased faster among more affluent socio-economic groups, leading to an increase in the survival gap between the least and most deprived patients.

Cancer Inequalities in London 2000-2004 showed the relationship between socio-economic deprivation and incidence and mortality of the majority of cancers.

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21 Department of Health, The NHS Cancer Plan, 2000
22 Gordon-Dseagu, V., op. cit.
was a strong positive correlation of incidence and mortality for lung cancer, head and neck cancer, cancer of the oesophagus, stomach, pancreas, bladder, and cervix with socio-economic deprivation. The reverse relationship was found between incidence of melanoma and breast cancer. For breast cancer, the highest incidence was in the highest socio-economic group, while the lowest socio-economic group had the lowest relative survival.\textsuperscript{24}

London demonstrates socio-economic gradients for survival after diagnosis of some cancers. The survival rate is worse for patients living in the most deprived areas for cancers of the head and neck, rectum, pancreas, breast, uterus, prostate, bladder, and skin (including melanoma). These poorer outcomes are likely to be related to late presentation, co-morbidity, and possibly differential access to treatment.\textsuperscript{25}

Excess deaths from cancer account for 20\% of the life expectancy gap between the London spearhead groups and England.\textsuperscript{26} Survival is consistently lower for patients living in spearhead PCT areas, than those in the rest of England.\textsuperscript{27}

\begin{center}
\begin{tcolorbox}
\textbf{Key message}

There is a significant variation in the incidence and mortality rates for cancer patients between London PCTs.
\end{tcolorbox}
\end{center}

2.3.4 Capacity

Population projections for London suggest an increase from 7.6 million in 2006 to 8.2 million in 2016.\textsuperscript{28} Figure 7 sets out the age distribution of this predicted increase.

\begin{flushleft}
\textsuperscript{25} London Health Observatory, \textit{The London Health Inequalities Forecast}, 2006
\textsuperscript{26} Ibid.
\textsuperscript{28} Coupland VH, Okello C, Davies EA, Bray F, Møller H, op. cit.
\end{flushleft}
It is expected that absolute numbers of cancers will increase. As shown in figure 7, in England the number of new cancer cases is predicted to rise by 33% by 2022, while in London they are only expected to rise by five per cent by 2022.\textsuperscript{29} This relatively smaller increase is due to London’s unusual demographic trends that predict a disproportionate increase in the middle age groups; those in the 65-85 age group, where cancer is more common, are not expected to increase. The absolute numbers of cancer cases will still increase in London and it remains important to ensure the resources available for cancer screening, early diagnosis, and cancer management, match the growing population requirements.

London’s cancer services serve the capital’s eight million population and also receive patients from a much wider area. This wider area population is not precisely defined but it has a higher predicted growth rate than London. The analysis indicates that the wider population for all cancers (predominantly rarer cancer services) is presently up to four million.\textsuperscript{30} The effective population served by London’s cancer services therefore lies between eight and 12 million.

**Key message**

Patients from outside London derived from a growing population and who receive treatment in London, will further increase the demand on London services.

\textsuperscript{29} Coupland VH, Okello C, Davies EA, Bray F, Møller H, op. cit.

\textsuperscript{30} HES inpatients 2005/07
2.3.5 Workforce

London has a number of unique workforce challenges. Turnover of NHS staff in London is higher than the national average, especially among inner city and teaching NHS trusts. There are high vacancy rates, particularly in some specialties, compared with the rest of England. As for many services in London, temporary staff are a substantial component. Students come to London from across the UK and overseas to train as healthcare professionals but many leave the capital after qualifying, preferring to work elsewhere.31

A Framework for Action32 reported that labour productivity is lower in London. For instance, doctors in a large acute hospital in London see 24% fewer patients than their counterparts in comparable hospitals elsewhere in England. Nurses also see relatively fewer patients.

A Framework for Action also indicated an inverse relationship between health need and GP distribution. Overall there are fewer GPs per head of weighted population in east and north London (where health need is greatest), compared with the south and west.

NHS London commissioned a preliminary study to support the cancer project work, to identify emerging workforce issues in the shape and scale of the cancer workforce over the next decade. The key issues are:

- Multidisciplinary teams must be able to sustain a critical mass of activity to maintain their skills.

- The National Chemotherapy Advisory Group (NCAG) recommends all hospital emergency departments have an acute oncology service and this will have implications on workforce productivity, demand for acute oncologists, and configuration.

- Roles that have started to emerge in the oncology workforce to improve quality and safety and meet rising demand, such as nurse-led chemotherapy, need to be transferable across London.

- Due to the variation in quality of cancer care across London, those who have poorer performance find it more difficult to recruit and retain non-medical staff.

2.3.6 Fragmentation of services

The spread of London’s cancer services is the result of historical development at various hospitals. This has taken place without a framework to consider how they fit into a connected system that can serve the entire London population. There has always been a competitive nature between London’s major hospitals. Poor planning across London also means current services do not make most efficient use of a limited, highly skilled workforce.

31 NHS London, Excellence in Health - Ensuring the Future, 2005
The lack of progress in implementing coordinated cancer services across London has led to service provision that may be excellent in some instances, but equally often provides patients with fragmented care, and therefore less than excellent care. Some progress has been made in London with the establishment of the PCT-led London Cancer Network Board.

This variation, plus a lack of critical level of activity (a minimum number of procedures undertaken in a particular speciality necessary for a service to sustain a consistently safe practice), places the quality and sustainability of these services at risk.

The Cancer Reform Strategy pointed to a division between hospital and community services that has been prolonged because of traditional professional working patterns. This division is compounded by variable primary healthcare services and difficulties in recruiting and retaining all professional groups in primary care.

Patient pathways and protocols need to reflect uniformity and equity of access for patients, particularly regarding continuity of diagnostic care, access to research (both scientific and health services research), consistent use of language regarding patient information, and standardised data reporting systems. A comprehensive IT infrastructure to support a quality service across the patient care pathway is not available across London, hampering the delivery of high quality care.

**Key messages**

- The lack of progress in implementing coordinated cancer services across London has led to service provision that may be excellent in some instances, but equally often provides patients with fragmented care.

- A comprehensive IT infrastructure to support a quality service across the patient care pathway is not available across London.

### 2.3.7 The provision of specialist services

"Due to historical configurations and organisational priorities, cancer care is not currently provided in the locations which are best for patient care. This includes too many acute providers; too many complex arrangements across different organisations and sites for multidisciplinary team meetings; and insufficient development of community care or primary care."

Public health consultant

Despite having the highest population density, London has one of the smallest average catchment populations per hospital for all services.\(^{33}\)

The London review of the 2004-2007 peer review programme set out the possible reasons for this:\(^{34}\)

'London has had a particularly high level of pre-existing specialist services in different trusts which made the designation of specialist teams more difficult to achieve than in most zones [...] the Capital] also has long established and strong institutional rivalries between trusts especially in inner London. The level of cooperation/integration between trusts is increasing but is still variable and continues to require a lot of time from networks to create compliant teams.'

This means that hospitals in London are not able to take full advantage of the advances in medical care as specialist staff, facilities, and patients are spread across a relatively large number of hospitals.

A Framework for Action also set out the arguments for centralisation of specialist services into fewer hospitals. There is evidence that demonstrates that surgical procedures usually have better outcomes if performed in specialist centres with high patient throughput. Cancer treatment in low volume hospitals, which tend to lack frequently practicing specialist teams and full facilities are, on average, associated with poorer outcomes.

An example where volume and specialisation relate to clinical excellence is seen at the Memorial Sloan-Kettering Cancer Centre in New York, where specialisation led to lower cost and better outcomes. Figure 8 shows the volume of patients treated in New York State against mortality and length of stay.

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Figure 8: Risk adjusted mortality from cancer against length of stay and number of patients treated (represented by size of circle) for institutions in New York State

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35 Ibid.
Data from cancer registries, although not consistent between regions, tends to suggest that specialised centres can achieve better survival rates among some groups of patients. A US study on a quarter of a million cancer patients undergoing resections found that peri-operative risk adjusted mortality, and long-term conditional survival worsened as hospital surgical volume decreased for all cancer types as set out in figure 9.

Evidence suggests that hospital mortality after surgery depends on the presence of teams with the ability to recognise complications and act on them swiftly. However, drivers for change must not be predicated on single parameters like surgical volumes. There are important additional drivers for change that merit careful consideration. Fully exploiting future medical advances and further improving cancer treatments will demand increasing sub-specialisation in many areas. These include medical and clinical oncology, using new surgical techniques, such as laparoscopic and robotic surgery; imaging; histopathology; and the use of increasingly sophisticated technologies. This will require hospitals to employ more appropriately highly trained clinical staff. This builds a strong case for fewer hospitals with greater expertise that are able to deliver high volume, high quality cancer care in a more cost-effective way, which also provides patients with better outcomes.

Working practices introduced by the European Working Time Directive require doctors to work fewer hours. As a result, there may need to be more consultant-based care. Moving to fewer, larger units may facilitate better middle grade resident on-call cover for acute services. There is also the need to fully utilise NHS staff in London, as doctors in the capital’s large acute hospitals see 24% fewer patients than their counterparts elsewhere in England.40

**Key message**

The numerous geographic and organisational boundaries between providers in London have hampered service development. As a result, Londoners have not fully benefited from advances in medical care as specialist staff, facilities, and patients are spread across too many sites.

2.3.8 Research

The delivery of world-class cancer care is dependent on factors beyond excellence in clinical service delivery. Evidence from the top cancer centres in the world indicates that research and development, teaching, and training need to be embedded in service delivery. The future sustainability of world-class cancer care in London depends on harnessing these synergies.

In London there are active teams producing high quality research in partnership with cancer research institutions. There are also three Academic Health Science Centres (AHSCs), of only five nationally, that are partnerships between academic medical research schools and leading NHS organisations. Given the concentration of these centres in London, and their world-class status, high quality research providers should support cancer services to further capitalise on improvements in cancer care. One of the major strengths of London is the high level of basic scientific expertise, providing opportunities in translational research. Patient numbers are sufficient to accelerate implementation of new developments into clinical practice, although such expertise is not currently fully utilised for patient benefit.

**Research and development**

Currently, organisational barriers in London hamper the ability to deliver clinical trials for patients locally, resulting in inequality of access to these trials.

For studies registered with the National Clinical Research Network in 2008/09, the five London cancer networks recruited 4,187 cancer patients into clinical trials. While this constituted 14.6% of the national total, uptake varied by network ranging from 366 patients in west London to 1,584 patients in south west London.41 This suggests unequal access to clinical trials across the capital.

Cancer patients who participate in clinical trials can have better outcomes.\textsuperscript{42,43,44} Generally all patients treated in an environment that undertakes clinical research do better, whether or not they are part of a clinical trial.\textsuperscript{45,46} It is thought that this is due to the inherent infrastructure associated with these centres and that staff at these hospitals are accustomed to closely adhering to treatment protocols.

Patients’ perceived experience of quality of care may increase with participation in a clinical trial.\textsuperscript{47} One study reported the major reason given by the patient for perceived clinical improvement was better follow-up received.\textsuperscript{48}

The systematic collection of all data, both bio-informatic and clinical outcome data, is vital not only to assessing effectiveness of clinical intervention but also in allowing academic outputs. The second review of the Cancer Reform Strategy observed that participation in national clinical audits is poor in London. High levels of participation are reported in north east and south west Strategic Health Authorities (SHAs), compared with a small minority of London trusts.\textsuperscript{49} Investment in information collection for commissioning purposes provides a good opportunity to form links with academic database collection, including bio-banks.

**Bench to bedside research – the arrival of personalised medicine**

London has a large population, but there is no London wide strategic approach to the development of new treatments collaborating with the pharmaceutical industry or universities (or cancer research institutions). Developing London tissue banks would allow pooling of valuable resources and enhance access to development of new targets and biomarkers of disease.

Commercial trial activity could be enhanced with London becoming the preferred provider for commercial trials of new drugs. This would have advantages for patients and commissioners. Patients will gain access to drugs not otherwise available; PCTs will not have to pay for these treatments; and providers will be able to generate income, as well as academic output. This would also draw in patients from around the periphery of London and further afield for larger clinical trials.

\textsuperscript{42} The Association of The British Pharmaceutical Industry, *Clinical Trials – Developing New Medicines*, 2003
\textsuperscript{43} CA Stiller, SJ Passmore , ME Kroll, PA Brownbill, JC Wallis & AW Craft, ‘Patterns of care and survival for patients aged under 40 years with bone sarcoma in Britain 1980-1994’, *British Journal of Cancer*, 2006
\textsuperscript{44} W Du, JH Reeves, S Gadgeel, J Abrams & WP Peters, *Cost-effectiveness and lung cancer clinical trials*, 2003
\textsuperscript{45} J West, J Wright, D Tuffnell, D Jaukowicz & R West, ‘Do clinical trials improve quality of care? A comparison of clinical processes and outcomes in patients in a clinical trial and similar patients outside a trial where both groups are managed according to a strict protocol’, *Qual.SAF Health Care*, 2005
\textsuperscript{46} JM Peppercorn, JC Weeks, EF Cook & S Joffe, ‘Comparison of outcomes in cancer patients treated within and outside clinical trials: Conceptual framework and structured review’, *Lancet*, 2004
\textsuperscript{48} Nurgat ZA, Craig W, Campbell NC, Bisset JD, Cassidy J, Nicolson MC, ‘Patient motivations surrounding participation in phase I and phase II clinical trials of cancer chemotherapy’, *British Journal of Cancer*, 2005
At present, there are over 1,000 anti-cancer drugs being evaluated through drug discovery and development programs throughout the world. These drugs offer the real prospect of improving outcomes for patients with malignant disease. However, optimal results are obtained when they are used in patient populations enriched for the drug target or likelihood of benefit. For example, the National Institute for Health and Clinical Excellence (NICE) recently approved a treatment for metastatic colorectal cancer, which is only approved for 60% of patients. This limited approval increases the cost-effectiveness of the treatment.50

Currently patients may receive systemic treatments where the benefit of the treatment for the individual patient may be relatively limited or difficult to quantify (for example adjuvant treatments). Current models are not cost-effective and are substantial drivers of escalating drug costs. Investment and prioritisation in predictive and prognostic biomarkers research should lead to enhanced outcomes, provide substantial savings to London’s NHS, and provide the tools to evaluate and introduce new treatments into clinical practice.

There is also a need to combine the basic elements of cancer research, including supportive care research and research on the impact of treatment on people affected by cancer, with the translational and clinical aspects. The experience in London, and at some centres internationally, is that this can considerably increase the transfer of basic discoveries into new therapeutic strategies.

**Case study: British Columbia Cancer Centre**

The British Columbia Cancer Centre seeks to enhance cancer control with focus on the translational research organisational model, linking pathway from discovery research to improved health outcomes, and vice-versa, by establishing a collective interdisciplinary resource across the domains of ‘discovery research’ (basic), clinical research, and population application.

To bring added focus to the translational research agenda, the organisation’s direction and resources are in three broad areas – the ‘discovery’ agenda of predictive and personalised cancer medicine; the ‘clinical’ or validation agenda of interventional cancer management; and the ‘population application’ agenda directed to population health and cancer.

**2.4 Section summary**

Developments in national policy for cancer services over the last few decades, changing cancer epidemiology, and demographic trends both nationally and in London, will impact on future service provision.

As a world-class city, there is a significant expectation that London’s cancer services meet the highest standards of care. The work performed in the capital is often

50 NICE, *Cetuximab for the first-line treatment of metastatic colorectal cancer*, NICE technology appraisal guidance 176, 2009
provided by experts in their field, recognised nationally and internationally. This section has described that London lacks a planned system for coordinating the delivery of services. An unplanned system cannot consistently achieve the standards of excellence in care exemplified by internationally recognised services in other cities.

Sections 3, 4 and 5 of this case for change set out in more detail the challenges for London in the areas of early diagnosis, common cancer and general care, and rarer cancers and specialist care.
3. Early diagnosis

England has poor cancer survival rates compared with other European countries and evidence suggests that later diagnosis is a major factor in this. The earlier cancer is diagnosed and treated, the greater the likelihood of survival, meaning earlier diagnosis has the potential to save lives. Improving survival rates to meet the best in Europe could translate to saving 1,000 Londoners’ lives per year. This section explains some of the issues currently preventing early diagnoses.

Late diagnosis may be occurring because of:

- poor recognition of the signs and symptoms of cancer and late presentation
- delays in primary care
- delays in referral to diagnostics and secondary care
- low uptake rates of screening programmes
- health inequalities.

The National Awareness and Early Diagnosis Initiative (NAEDI) pathway sets out the relationship between all of these factors.

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England has poor cancer survival rates compared with Europe.\(^{53,54}\)

### 3.1 Poor recognition of signs and symptoms

#### 3.1.1 Public awareness

In England, awareness of the early signs and symptoms of cancer is poor.\(^{55}\) Improving public awareness may increase early presentation and therefore early diagnosis.

Emerging findings from the NAEDI\(^{56}\) suggest that population groups differ in both the awareness of cancer signs and symptoms, and in perceived barriers to care.\(^{57}\) Understanding and responding to these differences may help reduce inequalities in London and improve early diagnosis.

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\(^{55}\) J Wardle, *NAEDI Newsletter*, National Awareness and Early Diagnosis Initiative, July 2008

\(^{56}\) The National Awareness and Early Detection Initiative (NAEDI), jointly led by the National Cancer Action Team (NCAT) and Cancer Research UK is a programme of activity to support local initiatives to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner.

\(^{57}\) K Elliott, *Cancer Awareness Measure, Getting Started Event*, National Cancer Action Team, June 2009
Measuring public awareness in a standardised way is difficult and consequently determining awareness levels, or evaluating the usefulness of interventions, is difficult. PCTs, along with networks, are currently undertaking baseline assessments of local need (relevant to early diagnosis) to establish variations in awareness.

Case study: Cancer awareness pilot initiative in two Lambeth pharmacies

Information leaflets on the signs and symptoms of certain cancers were made available at local pharmacies to people who may be experiencing them, in a health setting more frequently visited than a GP. People regularly obtaining medication for conditions with similar symptoms to those caused by lung cancer (such as persistent coughing, wheezing and chest pain) were targeted.

The pilot ran during April 2006, with two pharmacies and GP surgeries actively involved to test if the approach was acceptable to the public and practical to implement. It was hoped the information would encourage those at risk to seek advice from their GP sooner.

The pilot has subsequently become part of the pharmacy contract across all south east London PCTs.

3.1.2 Late presentation

“I believe the biggest challenge and biggest ongoing cause of avoidable cancer mortality and health inequality is late presentation. This is compounded by suboptimal uptake and coverage of the three screening programmes (particularly in inner London).”

Public health consultant

A person’s cancer pathway begins when they recognise and then act on signs and symptoms. A person who has a type of cancer with easily recognisable symptoms will present sooner. For example, breast cancer signs are more recognisable than those of colon cancer. Sometimes, despite recognising symptoms, people are reluctant to present to primary care. Evidence from an audit piloted in Scotland shows patients frequently have symptoms for a considerable period of time before seeking help (see figure 10).

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58 C Burton et al, Evaluation of a cancer awareness pilot initiative in two Lambeth pharmacies, August 2006
Late presentation is a contributing factor to the late diagnosis of cancer. More exploration is needed to understand patients’ reluctance to come forward.

Evidence has shown that country specific one year and five year survival rates are lower in the UK than other countries in Europe. A contributing factor to this was late presentation and therefore an advanced stage of disease at diagnosis. A study in north east London showed inferior one year survival rates after the diagnoses of women with breast cancer compared with the rates for women elsewhere in London. Of the women who survived one year after their diagnoses, their survival to five years equalled that of other women in London. With the speed that breast cancer develops, the north east London data infers that late presentation was a contributing factor to lower survival rates.

For patients diagnosed for all malignancies between 2000 and 2004, one year cancer survival varied significantly across the London cancer networks, ranging from 63% to 70.7%.

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3.2 Delays in primary care

Cancer can be difficult to diagnose in its early stages. Early symptoms can be non-specific and similar to those of other non-malignant conditions. These factors, together with the few cancer cases that GPs see per year, can mean GPs may delay sending patients for diagnostic tests or referring them for a consultant’s opinion. Historically GPs have acted as gate-keepers to healthcare provision and can avoid referrals of patients with minimal or vague symptoms.

The Cancer Reform Strategy proposed undertaking a national audit in primary care of newly-diagnosed cancers, to inform decisions about how best to support primary care professionals and ensure the earliest diagnosis. The audit will be carried out retrospectively, in cancer networks, on a case by case basis, to uncover any pre-diagnostic delays.

When published, this audit will provide a locality specific baseline for developing GP interventions to improve a cancer patients’ diagnostic pathways. This will need to be associated with Significant Event Audit to gain a deeper understanding of any pre-diagnostic delays taking place.

“More support and better protocols are needed for GPs to identify patients at risk and more training in listening to their patients.”

Healthcare for London patient panel member

Key message

Poor public awareness levels of the signs and symptoms of cancer, late presentation, and the difficulty for primary care to diagnose cancer early, can result in a delayed diagnosis.

3.3 Referral to diagnostics

“Appropriate and timely movement of patients [...] is hampered by incompatible records. This necessitates faxing, emailing and photocopying files. It is a practice that is both wasteful and a continued risk.”

Consultant urologist

Prompt access to appropriate diagnostics and referral to specialists is fundamental to ensuring early diagnosis and improved survival. The NICE guidelines on referral for suspected cancer have been developed to help GPs decide when to refer to

63 Department of Health, Referral guidelines for suspected cancer, 2000
64 NICE, CG27 Referral for suspected cancer, 2005
secondary care specialists. The guidelines also recommend diagnostic tests that should be accessed prior to specialist referrals.

Referral categories are:

- Immediate: an acute admission or referral in a few hours.
- Urgent: the patient is seen in the national target for urgent referrals of 14 days (two-week referral route).
- Non-urgent: all other referrals.

Despite NICE guidelines, there are still delays to patient diagnoses. Poor one year survival rates after diagnosis may indicate delayed referrals. It suggests that when a person first presents to specialist care their disease has reached an advanced stage. The London cancer networks showed survival rates in all cancers diagnosed from 2001 to 2005 ranged from 61-70%. A similar variation is seen across England.

3.3.1 Access

GP practices have limited and variable access to diagnostics to exclude a diagnosis of cancer. This includes routine blood tests, X-rays, ultrasound scans and proctoscopies, as well as some more lengthy and invasive tests. However, the Government has recently pledged speedier access to key diagnostic tests for GPs to enable them to exclude a diagnosis of cancer.\(^{65}\)

The majority of patients referred with symptoms that may suggest underlying cancer do not actually have cancer. To avoid creating anxiety for the patient, GPs do not always advise the patient of the investigations’ urgency. This increases the risk that the patient may postpone hospital appointments leading to further delay in diagnosis.

**Case study: Community-based flexible sigmoidoscopy in north east England**

The introduction of community-based flexible sigmoidoscopy in north east England has improved GP access to diagnostic tests and greatly reduced referrals to specialist colorectal clinics, while improving early diagnosis of colorectal cancer. Evidence has shown that flexible sigmoidoscopy accompanied by a full blood count and abdominal examination, is an adequate initial diagnostic work-up for patients with new lower gastrointestinal symptoms.\(^{66}\)

In London, the majority of newly diagnosed cancers do not arise through the two-week referral route. For example, data from the west London cancer network shows that 67.9% of newly diagnosed cancers were diagnosed through non-urgent referral. This is 10% higher than the national average (57.8%).\(^{67}\) Currently, the protocols are unclear for acting promptly on the receipt of abnormal results in secondary care.

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\(^{65}\) [http://www.labour.org.uk/gordon-brown-speech-conference] [accessed October 2009]


\(^{67}\) [https://www.cancertoolkit.co.uk/Default.aspx]
can result in suspected cancer patients not receiving an early referral, a definitive specialist diagnosis and subsequent treatment. Direct early referrals may already take place in some cases. For example, from radiology, where a test result indicates urgent referral to the relevant tumour multidisciplinary team is required, results are sent back to the original referrer. Although, this does not happen in all cases. Consultants do have the ability to upgrade routine GP referrals to the urgent two-week pathway; however, details of these consultant upgrades are not always reported back to GP practices and PCTs.

### Key message

Primary care has limited diagnostic facilities to exclude a diagnosis of cancer and there are no clear protocols for acting on the receipt of abnormal results in secondary care.

#### 3.3.2 Referrals in secondary and specialist care

GPs should comply with the NICE guidelines for access to urgent diagnostics and referral for diagnosis to secondary care. Although this should also apply to secondary care clinicians caring for patients in non-cancer settings, there are problems surrounding the accuracy of referrals. This applies to primary and secondary care, and from secondary to specialist care following an initial suspected cancer case. Studies have shown most patients referred under the two-week waiting time rule did not have cancer.68,69,70,71Audit findings have shown that over half of patients presenting with cancer symptoms did not fit NICE guidelines.72

Data from the Cancer Commissioning Toolkit show that when compared with the national level, London has a lower percentage of urgent referrals that result in a diagnosis of cancer (for almost all cancer types).73 This large number of urgent referrals not resulting in a diagnosis can lead to an overloaded system. Patients referred non-urgently who have cancer are therefore experiencing delays. Trusts are now required to provide feedback to GPs about the working of the two-week rule, and an emerging issue relates to the appropriateness of the referral guidelines themselves. It is clear the NICE guidelines on referrals can be met and still be deemed ‘inappropriate’ by the consultant. Conversely, a significant number of patients who do not meet the referral criteria can present with a high suspicion of cancer, appropriate for urgent evaluation.

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69 K Thorne et al., ‘The effects of the Two-Week Rule on NHS colorectal cancer diagnostic services: a systematic literature review’, BMC Health Services Research, 2006, 3;6:43
72 National Cancer Action Team, Cancer Action Newsletter, June 2008
73 <https://www.cancertoolkit.co.uk/Default.aspx>
3.3.3 Service provision

London lacks coordinated diagnostic teams, comprising of qualified specialised staff, that carry out a range of investigations on the same day in an outpatient appointment. This can mean lengthy waits for diagnostic testing, as well as lengthy waits for test results. Consequently there are delays in obtaining a definitive diagnosis. The current fragmented organisation of these services could be improved and made more efficient and effective. Evidence clearly highlights the potential benefits of consolidation, which networks can bring in terms of quality, safety, workforce development, efficiency and cost-effectiveness.\(^\text{74}\) Additionally, the absence of a stable and secure mechanism of sharing data and images across London trusts and networks can cause delays in diagnosis and lead to the duplication of tests.

Key messages

The current configuration of diagnostic teams across London is causing delays along the diagnostic pathway.

The absence of a stable and secure mechanism of sharing data and images across London trusts and networks can cause delays in diagnosis and lead to a duplication of tests.

3.4 Low uptake of screening programmes

Screening makes an important contribution to the early diagnosis of some cancers. There are national screening programmes for cervical, breast and bowel cancer with research being carried out on screening for prostate and lung cancer.

The second annual review of the Cancer Reform Strategy highlighted London PCT’s relative poor performance in screening coverage.\(^\text{75}\) For cervical screening, 24 of London’s 31 PCTs were in the lower (worse) quartile and only two in the upper quartile, compared with the rest of England. For breast screening coverage, 26 of London’s PCTs were the lower quartile with no PCTs in the upper quartile.


\(^{75}\) Department of Health, Cancer Review Strategy – achieving local implementation: Second annual report, December 2009
Over a third of breast cancer cases are detected through the breast screening programme in London. Women whose cancers are screen detected have a significantly greater chance of survival.\textsuperscript{76}

3.4.1 Coverage

Coverage is the percentage of the eligible population that have been screened in the last three years. By way of example of a cancer screening programme, figure 11 shows the breast screening coverage across London PCTs for 2007.

![Figure 11: Breast screening coverage by PCT ages 53-70, 2007/08](image)

<table>
<thead>
<tr>
<th></th>
<th>Greater than 70%</th>
<th>60 – &lt; 70%</th>
<th>50 – &lt; 60%</th>
<th>&lt; 50%</th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>63.59%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>73.90%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: London Quality Assurance Reference Centre (QARC).

Compared with the rest of the country, London has a lower uptake rate of screening programmes. The national minimum targets of 70% for breast and 80% for cervical screening are largely not met, although there is considerable variation between PCTs. For 2007/08 uptake rates for breast screening show London has the lowest rates out of the 10 SHAs in England,\textsuperscript{77} where the average uptake rate is 75%.\textsuperscript{78}

Figure 12 shows there has been no increase in the number or proportion of women in London screened for breast cancer over the last three years.

\textsuperscript{76} International Agency For Research On Cancer, \textit{7th Handbook on Cancer Prevention}, 2002
\textsuperscript{78} The London Assembly - Health and Public Services Committee, \textit{Behind the Screen: Breast Screening Uptake and Radiotherapy waiting times in London}, March 2008.
To increase the early diagnosis rate of cancer this will need to be improved. A new guideline published by NICE and the National Collaborating Centre for Primary Care (NCCPC) sets out how health professionals should identify and care for women who are at risk of developing breast cancer because of a family history of the condition (familial breast cancer).\(^{81}\) This has not yet been implemented in London.

The London Specialised Commissioning Group has undertaken a review of the breast screening programme in London. The main finding was that although uptake rates vary between London PCTs, lower rates are more prominent in areas with high levels of deprivation. Deprivation does not completely explain this variation as there is poorer attendance for breast cancer screening by black women. This is thought to be possibly due to cultural differences such as a lack of awareness of the benefits of screening or a belief that they are not at risk.\(^{82}\) Recent targeted, health promotion work in Tower Hamlets (where uptake increased by nearly 20% in a year) suggests that substantial improvements are possible.

For London there are a range of factors that contribute to a low uptake of screening programmes. There is a lack of understanding by some about the value of screening and a significant number of people in hard-to-reach groups, such as prisoners, travellers and the homeless, who may not receive an invite at all. Evidence also suggests black and minority ethnic (BME) communities are less likely to accept their screening invite and response to routine invitations for breast screening for women was significantly lower for South Asian invitees.\(^{83}\) With regard to breast screening, the transient nature of certain populations in the capital has resulted in inflating and conflicting patient lists. Many of these lists are out of date and require validation if the correct population groups are to be called. There are also problems with GP catchment areas, which result in patients being called to screening services in the wrong borough. Also, at present, there is no standard IT system to support call and recall centres resulting in a lack of flexibility in access and appointments.

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\(^{79}\) London Quality Assurance Reference Centre (QARC), *London Breast Screening Programme Annual Results April 1st 2007 to March 31st 2008*.  
\(^{80}\) The total of women screened includes GP and self referrals which are not included when calculating the invitation uptake rate.  
\(^{81}\) National Collaborating Centre for Primary Care, *Familial breast cancer, The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care*, 2006.  
The London Assembly’s report on screening uptake in London concluded that low uptake rates for screening were in part due to a lack of knowledge about the reasons why women do not attend and the characteristics of non-attendees, which reduces the ability of the service to respond to changing needs. The report also suggests London women’s poor experiences of the screening programme as reason was low uptake.

**Key message**

Screening has an important contribution to early diagnosis and improved outcomes. London has a lower uptake of screening programmes than the rest of England.

### 3.5 Inequalities

Health inequality can be defined as the avoidable variation between groups in health and disease prevalence and outcomes, or in quality of care. Some groups and communities have higher incidence rates of particular types of cancers. Currently, these incidence rates are not understood by those who commission services for the local population.

London has a high level of deprivation where 20% of wards are in the 10% of the most deprived wards in England. Section 1 described a link between socio-economic deprivation and incidence rates of cancer and outcomes. With the exceptions of melanoma and breast cancer, higher levels of deprivation are associated with higher incidence rates of cancer and poorer survival rates. Figure 13 sets out affluence and deprivation levels of local populations in London.

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As well as the link between socio-economic deprivation and poorer outcomes, the awareness of the symptoms and risks of cancer is lower in more deprived groups. Across a range of cancer types, people from more deprived areas tend to delay seeking help for longer than those from more affluent backgrounds.\textsuperscript{86}

Understanding the demography of local populations is crucial to understanding inequalities and deciding priorities for action. Inequalities in seeking medical advice and treatment can result in late diagnosis, which can lead to a substantial number of avoidable deaths.

Some communities are more likely to develop cancer than others and there are inequalities in access to services for hard-to-reach groups, such as BME groups, prisoners, travellers and homeless people. In addition, there are other factors that such as inequalities in the early diagnosis of cancer include age, gender, ethnicity, learning disabilities, sexual orientation, and mental health.

3.5.1 Age

Cancer occurs predominantly in older people and for adults, the relative survival rates of cancer decrease with age. Nearly three-quarters (74\%) of cancer cases are diagnosed in people aged 60 and over, and more than a third of cases in people aged 75 and over as set out in figure 14.

3.5.2 Gender

While some cancers are gender specific and others affect one gender significantly more than the other, the age standardised mortality rates for the 10 most common cancers affecting both genders in every case higher in men. Whether the differences in mortality rates relate to differences in lifestyle choices, smoking prevalence or later presentation is not fully understood.\(^87\)

Figure 15: Age standardised mortality in England per 100,000 population\(^88\)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>55.8</td>
<td>28.4</td>
</tr>
<tr>
<td>Colorectal</td>
<td>24.0</td>
<td>14.7</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>13.0</td>
<td>5.1</td>
</tr>
<tr>
<td>Stomach</td>
<td>10.9</td>
<td>4.3</td>
</tr>
<tr>
<td>Pancreas</td>
<td>9.6</td>
<td>7.3</td>
</tr>
<tr>
<td>Bladder</td>
<td>9.1</td>
<td>3.0</td>
</tr>
<tr>
<td>Non-Hodgkin’s Lymphoma</td>
<td>7.5</td>
<td>4.7</td>
</tr>
</tbody>
</table>

\(^87\) Department of Health, Cancer Reform Strategy, 2007
\(^88\) Ibid.
Leukaemia | 6.8 | 4.3  
Kidney    | 6.1 | 2.3  
Melanoma  | 2.7 | 1.9  

3.5.3 Ethnicity

Research on cancer incidence and survival rates among BME communities has been conducted by the National Cancer Intelligence Network. Overall, the incidence of cancer in the minority ethnic population is lower than in the white British population.

Findings include:

- Asian, Chinese and mixed ethnic communities have a significantly lower risk (20-60%) of developing cancer when the all malignancies combined group were examined.

- The Asian community has significantly higher incidence rates for the following cancer types:
  - Liver cancer is between 1.5 and three times more likely.
  - Cancer of the mouth and cervical cancer is significantly higher for Asian females aged 65 years and over.

- Black males of all ages are significantly more likely to have a diagnosis of prostate cancer.

- The Black community has higher incidence rates of stomach cancer, liver cancer, and myeloma for those aged over 65 years.

- Asian and Black females, aged 65 years and over, are at higher risk of developing cervical cancer.

- Black women are recognised to have a higher incidence of triple negative breast cancer and at an earlier stage.

Case study: Breast cancer in south east England

Studies from south east England have shown variations in breast cancer incidence, stage distribution, treatment and survival between ethnic groups.

All ethnic groups studied had lower age-standardised breast cancer incidence rates

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than white women, with Bangladeshi women having the lowest rate. Black African women were the least likely to have a record of cancer surgery or hormone therapy, and most likely to receive chemotherapy. This ethnic group also had significantly worse overall survival rates.

These findings suggest that a strategy of earlier detection should be pursued in Black African women to increase survival rates.

Awareness of signs and symptoms of cancer is generally lower amongst BME groups. This may reflect later presentation among minority ethnic groups. Currenty, health promotion materials are not always provided in an easy read format or translated into community languages which can make it difficult for some groups to understand key signs and symptoms of cancer or the importance of screening.

3.5.4 Learning disabilities

Awareness of cancer is likely to be particularly low among people with learning disabilities. There is evidence to suggest that those with learning disabilities experience inequalities in access to cancer screening programmes. Figures show the uptake rate for breast screening is 76% for all women in the UK but between 17% (for those with family care) and 52% (for those with formal care) for women with learning disabilities. For cervical screening, the uptake rate for all women in the UK is 85%, but for those aged over 18 with learning disabilities, the uptake rate is between three per cent (for those with family care) and 17% (for those with formal care). Some variation is attributable to the considerable issues relating to consent. For example, there are large numbers of women with learning disabilities who will not cooperate and withdraw their consent during breast screening tests.

3.5.5 Sexual orientation

Evidence shows there is a relationship between sexual orientation and inequalities in cancer incidence. For example, gay men have a higher incidence of anal cancer (HPV related) and HIV/AIDS related cancer. Lesbians, may be at higher risk of breast cancer as they may be less likely than heterosexual women to have children. There is also a link between sexual orientation and access to cancer screening programmes. For example, compared with seven per cent of women in general, 15% of lesbian and bisexual women over the age of 25 have never had a cervical smear test. One in 50 lesbian and bisexual women has been refused a test, while others have been told that they are not at risk of developing cervical cancer.

3.5.6 Mental health

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96 R Hunt & Dr J Fish, Prescription for Change, Lesbian and bisexual women’s health check, 2008
Recent research shows people with schizophrenia have an increased risk of developing bowel cancer.\(^{97}\) However, there is conflicting evidence on whether people with schizophrenia have a different risk of cancer from the general population. A study to determine the risk of common cancers in patients with schizophrenia or bipolar disorder found that, after adjustment, patients with schizophrenia had a 190% increased risk of colon cancer; a marginal increased risk of breast cancer; and a 47% decreased risk of respiratory cancer.

Furthermore, patients taking anti-psychotic drugs were three times more likely to develop colon cancer.\(^{98}\) However, a recent review of eight population-based studies showed that the pooled overall cancer incidence in patients with schizophrenia and their first-degree relatives was not significantly increased. Lung cancer incidence in both males and females, and breast cancer in females, increased for those patients with schizophrenia compared with general population samples.\(^{99}\)

Additionally, there is evidence to show that those with a mental health problem are more likely to postpone presentation when they have cancer symptoms, delay the diagnostic process and present with more advanced cancer.\(^{100}\)

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**Key message**

Inequalities in incidence and access exist based on age, gender, ethnicity, disability, sexual orientation and socioeconomic status. This can affect the early and timely diagnosis of cancer.

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**3.6 Section summary**

This section set out the issues in London regarding the early recognition of signs and symptoms, referral to diagnostics, screening uptake rates, and health inequalities.

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\(^{97}\) Cheshire and Merseyside Bowel Screening Programme, *Bowel Cancer and Bowel Cancer Screening*, accessed October 2009

<http://www.mccn.nhs.uk/documents/bowel_pdu/Western%20Cheshire%20Mental%20Health%20BCSP%20Sessions.ppt>

\(^{98}\) J Hippisley-Cox et al, ‘Risk of malignancy in patients with schizophrenia or bipolar disorder: nested case-control study’, *Archives of General Psychiatry*, December 2007


\(^{100}\) Kunkel et al., ‘Consultation for ‘maladaptive denial of illness’ in patients with cancer: psychiatric disorders that result in non-compliance’, *Psycho-oncology*, 1997
4. **Common cancers and general care**

Common cancers were defined for this project based on consultation with clinicians and London’s projected incidence rates – those with a predicted incidence in 2020 of more than 1,000 per million, as shown in figure 16.

Incidence data on non-melanomas, although high, is unreliable so only melanoma is shown. However, skin cancer as a whole is taken to be a common cancer.

The following types of cancers fall under the common cancers workstream:

- breast cancer
- lung cancer
- colorectal cancer
- bladder and prostate cancer
- haematological cancer
- skin cancer (melanoma and non-melanoma).

**Figure 16: Predicted common cancer incidence in London 2001-2020**

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Incidence 2001</th>
<th>Incidence 2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>4151</td>
<td>4412</td>
</tr>
<tr>
<td>Lung</td>
<td>3744</td>
<td>3326</td>
</tr>
<tr>
<td>Prostate</td>
<td>3004</td>
<td>3495</td>
</tr>
<tr>
<td>All colorectal</td>
<td>3074</td>
<td>3401</td>
</tr>
<tr>
<td>All haematological</td>
<td>2348</td>
<td>2686</td>
</tr>
<tr>
<td>Bladder</td>
<td>934</td>
<td>1071</td>
</tr>
<tr>
<td>Melanoma*</td>
<td>541`</td>
<td>705</td>
</tr>
</tbody>
</table>

* Non-melanoma skin cancers excluded due to unreliability of incidence data

Most areas of London were under performing in 2005 when compared with international survival rates for breast, colon and lung cancers, as shown in figure 17.

Section 2 noted that London patients have reported a poorer experience of cancer services than those elsewhere in the UK. In the same study it was reported that prostate cancer patients have a worse experience than those with other cancers.\(^{102}\)

This section also sets out the case for change for the delivery of the following cancer services:

- chemotherapy
- radiotherapy
- multidisciplinary teams
- bed days
- follow-up and support
- rehabilitation
- palliation.

These services apply to the delivery of all cancers, including the management of rare cancers as detailed in section 5.

4.1 Common cancers

4.1.1 Breast cancer surgery

Almost 41,000 women were diagnosed with breast cancer in England and Wales in 2006.\footnote{Cancer Research UK, www.info.cancerresearchuk.org, 2009} This is the most common type of cancer in women (and has the highest incidence of all cancers), accounting for nearly 30% of all cases of cancer in women.\footnote{NICE, Improving outcomes in breast cancer: manual update, 2002} The lifetime risk of developing breast cancer is almost 11%.\footnote{MJ Quinn, P Babb, A Brock, et al, Cancer Trends in England and Wales 1950-1999 Studies on Medical and Population Subjects no.66, The Stationery Office, 2001}

The treatment of primary breast cancer (cancer that has not spread beyond the breast) usually involves surgery, either breast conservation (wide local excision) or mastectomy (and in some cases surgery to the axillary lymph nodes). Normally, surgery is followed by adjuvant treatment such as radiotherapy, chemotherapy or hormone therapy, or a combination of these. These types of therapy may infrequently be given before surgery.

NICE guidance for breast cancer recommends that breast surgeons should be separate from general surgeons:

‘Specialists in the management of breast cancer are likely to have higher levels of expertise and skills. If general surgeons for whom breast care is not a specialist interest pass this work to specialist teams, reductions in morbidity and mortality among patients may be anticipated.’\footnote{NICE, Improving outcomes in breast cancer: manual update, 2002}

A study of almost a quarter of a million breast cancer patients showed high volume in surgical intervention on primary breast cancer is associated with better outcomes.\footnote{U Guller, S Safford, R Pietrobon, et al, ‘High hospital volume is associated with better outcomes for breast cancer surgery: analysis of 233,247 patients’, World Journal of Surgery, 2005, 29/8; 994-999} Peri-operative mortality has been found to be higher for patients operated on at low volume hospitals (those seeing 30 cases or less a year) after breast-conserving therapy, compared with patients operated on at high volume hospitals (those seeing 70 cases or more a year). High volume hospitals had significantly lower non-routine patient discharge and post-operative morbidity, and a shorter average length of stay.

NICE Improving Outcomes Guidance (IOG) for breast cancer stipulates teams should see a minimum of 100 new cases per annum. The Association of Breast Surgery surgical guidelines recommend an annual surgeon caseload of at least 30 treated breast cancers.\footnote{Association of Breast Surgery at the British Association of Surgical Oncology, Surgical guidelines for the management of breast cancer, 2009}

Figure \ref{fig:18}\footnote{Much of the data in this report is generated from hospital episode statistics (HES) data. Where this is the case, this has been noted. HES data is routinely used by NHS trusts and is submitted to the Department of Health, allowing hospital activity to be monitored centrally. Despite these issues, HES data remains the most reliable form of data available to inform the project, and is routinely used on a national level to investigate hospital activity.} shows there is considerable variation in the number of procedures for breast cancer carried out in London’s provider organisations. This variation would be even greater, if surgeons per provider was considered.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure18.png}
\caption{Figure 18 shows there is considerable variation in the number of procedures for breast cancer carried out in London’s provider organisations. This variation would be even greater, if surgeons per provider was considered.}
\end{figure}
There are 22 NHS providers of breast cancer surgery in London, 17 of which (77%) performed less than 300 mastectomies and other breast excisions in 2007/08. Elsewhere in the capital, one provider carried out almost 800 such procedures in 2007/08.

Since the NICE guidance was published, there has been substantial restructuring and the majority of providers are compliant with the minimum requirement. However, peer review has identified inherent frailties in the composition of surgical teams in London. The National Mastectomy and Breast Reconstruction Audit set out the following determinants of high quality in breast cancer surgery: \(^{111}\)

- service configuration
- resources
- communication with patients
- time to allow informed and reasoned decision-making
- training of staff
- communication between clinicians

• defining and auditing quality standards and outcomes.

There is also considerable variation in surgical practices among London’s providers of breast cancer surgery. A Framework for Action proposed that many procedures, including breast cancer surgery, could be provided as day cases. Some London providers are already conducting up to 90% of those procedures grouped as ‘other excision of breast’ as a day case procedure; however, many carry out less than half of these procedures in the day case setting. Similarly, some women having mastectomies are not given access to immediate reconstructive surgery.

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Day surgery takes a more conservative approach to surgery so patients can return home sooner, where appropriate, which has proven to be popular with patients. A 1991 Audit Commission report found patients were positive about receiving day surgery.112 Day cases are also much more cost-effective for the NHS.113

For individual surgical specialities, London has day surgery rates of just 38% for gynaecological surgery and 37% for breast cancer.114 The British Association of Day Surgeons recommends the day case rates for these specialties should be 76% and 63% respectively.

**Case study: Day case breast cancer surgery**

One south London trust has changed its breast cancer surgery service over two years, increasing its rate of day surgery to over 90% of cases. This has been achieved by

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114 Ibid.
implementing system changes and changes in surgical practice. The latter includes ceasing drain usage and seroma aspiration, using advanced suturing techniques and applying aggressive management of wound problems.

System changes include carrying out robust pre-assessment checks, promoting enhanced working between the breast team and day surgery, and conducting formalised telephone questionnaires post surgery. The patient experience has improved, validated through externally administered focus groups.

Drivers for change

The move towards day surgery for breast cancer, the provision of immediate reconstructive surgery, and the use of new surgical techniques and technology require a concentration of specialist multidisciplinary staff and facilities to deliver these streamlined practices. Concentrating services provides a clinical environment to deliver these best practice developments in surgery.

Case study: Sentinel Lymph Node Biopsy

Four UK trusts are piloting fast-track intra-operative assessment of Sentinel Lymph Node Biopsy, which incorporates two technologies that aim to identify metastatic spread intra-operatively in 45 minutes so a second operation can potentially be avoided.

Initial findings suggest around 8,000 second surgeries, with an average length of stay of up to six days, could be avoided. This would improve patient outcomes, improve patient experience and save around 8,000-48,000 bed days in the UK per annum.115

Key messages

Variation in day case rates for breast cancer surgery across the capital points to a variation in quality of treatment, with some women not being given access to day case procedures or to immediate reconstructive surgery.

Appropriate settings for common cancer surgical procedures should be considered. To drive continuing improvements further concentration of services may be required to provide a clinical environment that enables a platform for the delivery of best practice developments in surgery.

4.1.2 Lung cancer surgery

Lung cancer is the most common cancer diagnosed in England and Wales in both genders, with an estimated 31,000 people diagnosed with the disease each year.116

Lung cancer is the second most common cancer in men after prostate cancer and the third most common cancer in women after breast and bowel cancer. It is the commonest cause of death from cancer in both men and women.

There are two broad types of tumour – non-small cell lung cancer and small cell lung cancer. Non-small cell lung cancer accounts for about 80% of cases and only about 10-15% of patients are suitable for surgery to remove the tumour.\textsuperscript{117} Small cell lung cancer is rarely treated by surgery.

The NICE guidance for lung cancer states that radical surgery offers the chance of long-term survival for a minority of patients and so every effort should be made to identify those who might benefit.\textsuperscript{118} Increasing the rate of appropriate surgery is likely to maximise the potential benefits by reducing morbidity and mortality. The National Lung Audit\textsuperscript{119} reported, albeit with incomplete data, that surgical resection rates are low and proposed they be reviewed if they are below 11%. It also found the use of anti-cancer treatments, such as surgery, chemotherapy and radiotherapy, was low at 48% when compared with international standards.

Lung cancer is a common cancer treated with a rarer procedure, thoracic surgery, which is only undertaken on patients diagnosed with early stage disease. The procedure should become much more common as early presentation and diagnosis improves. Not all surgeons treating lung cancer are specialist thoracic surgeons, many are cardio-thoracic surgeons. Thoracic surgery should be represented on all multidisciplinary teams.

In London, there are seven providers of lung excision surgery. The volume of lung excision procedures carried out by these providers in 2007/08 ranges from over 200 to below 50. Four of the trusts carried out less than 100 lung excisions last year.

\textsuperscript{116} www.nhs.uk/conditions/Cancer-of-the-lung/Pages/Introduction
\textsuperscript{117} NHS Executive, \textit{Improving outcomes in lung cancer: the guidance}, 1998
\textsuperscript{119} NHS England, \textit{National Lung Cancer Audit}, 2009
Drivers for change

While there is no evidence of the minimum volume that providers should be treating in a year, concentrating services will provide a clinical environment that delivers best practice in lung cancer surgery.

There also appears to be a correlation between higher volume and shorter average length of stay among London providers. The overwhelming picture though, is of the great variation in the average length of stay between these providers. One trust has a mean length of stay of just eight days; another keeps patients in hospital for almost double that.

While some variation in length of stay between providers is natural, differences of this scale indicate variation in processes and clinical practice. This means there is variation in the quality of service that Londoners experience. The NHS in London must work to ensure quality care is delivered consistently across the capital.

Key message

Thoracic surgery does not currently provide input into all lung multidisciplinary teams in London.

Lengths of stay for common surgical operations need to be reduced and care should be consistently delivered across London. Providers carrying out larger volumes should
put systems in place to reduce length of stay through economies of scale.

4.1.3 Colorectal cancer surgery

Colorectal (large bowel) cancer is the second most common cancer overall after lung cancer in England and Wales, in terms of both incidence and mortality. Colorectal cancer affects both genders. Each year over 30,000 new cases of colorectal cancer are diagnosed, and colorectal cancer is registered as the underlying cause of death for about half this number.\textsuperscript{120}

Surgery to remove the primary tumour is the principal first-line treatment for around 80\% of patients, of which about 40\% will remain disease free in the long-term.\textsuperscript{121}

Guidance for colorectal cancer states the majority of surgery should take place in elective care settings, but these must be organised with access to designated diagnostic services including colonoscopy, computerised tomography (CT) and magnetic resonance imaging (MRI).

Drivers for change

The increased use of laparoscopic surgery in treating colorectal cancers has been approved by NICE, but is not widely available with only 5-10\% of surgeons trained to use this technology. As a result, not all colorectal multidisciplinary teams in London include a fully trained laparoscopic surgeon. The benefits of this less invasive surgical technique are lower morbidity, speedier recovery and reduced inpatient days, which could be reinvested to improve patient care further. Evidence on laparoscopic surgery for cancer of the colon shows it is as effective as open surgery in the short-term and is likely to produce similar long-term outcomes.\textsuperscript{122}

NCAT is currently collecting data on the use of laparoscopic techniques in colorectal surgery in London. The provisional data is shown in figure 21.

\textsuperscript{120} NICE, \textit{Improving outcomes in colorectal cancer: manual update}, 2004
\textsuperscript{121} Ibid.
\textsuperscript{122} PJ Guillou, P Quirke, H Thorpe, et al, \textit{Short-term endpoints of conventional versus laparoscopic assisted surgery in patients with colorectal cancer (MRC CLASICC trial): multicentre, randomised controlled trial}, 2005
Twenty-five providers carried out colon resections in London last year. The use of laparoscopic surgery by these providers is variable, ranging from under five per cent to almost half of total colon resections.

A number of operations, including abdominoperineal excision (APE) and anterior resection, are available to excise rectal tumours. The traditional curative procedure has been the APE. While this operation may be the only option in patients with very low rectal tumours, the alternative technique of anterior resection may be performed when appropriate.

A recent publication reported wide variation in the use of APE and anterior resection for treatment of low rectal cancers among individual surgeons across the UK. Although the data must be interpreted with caution, APE rates from under 10% to almost 50% were reported. Assuming the case mix is the same for most surgeons, it is expected that the variation in rates should be much narrower. Every effort should be made to ensure the appropriate surgery is undertaken for all Londoners. Where APE is deemed to be the appropriate operation, surgery must include the levators.

Some early rectal cancers may be best treated using trans-anal endoscopic microsurgery (TEM). To date, the demand for this in London has been low but the new national bowel cancer screening programme is likely to identify more patients with early stage cancers, increasing the demand for this procedure.

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Key messages
The current service configuration in London for colorectal cancer surgery needs review.
All colorectal multidisciplinary teams in London do not include a fully trained laparoscopic surgeon.

4.1.4 Bladder and prostate cancer surgery

Prostate cancer is the most frequently diagnosed cancer among men. It is particularly common among older men; two-thirds of those who die from prostate cancer are over the age of 75.\textsuperscript{124} When prostate cancer does develop in younger men, it seems to have a more aggressive nature. Relatively few of the 40-49 age group are affected but these men have the highest mortality rate.\textsuperscript{125}

Cancer of the bladder may develop in either gender but is roughly twice as common in men.

An average local hospital, serving a population of 200,000, would treat an estimated 70 men with prostate cancer and 50 people with bladder cancer every year. Approaches to treatment range from active monitoring to radical surgery to radiotherapy.\textsuperscript{126}

NICE guidance for urological cancers states that radical surgery for common urological cancers (prostate and bladder cancer) should be provided by teams typically serving populations of one million or more, and carrying out a cumulative total of at least 50 such operations a year.\textsuperscript{127}

A review of the literature on urological cancers showed specialist hospitals and surgeons that treat more patients achieve better outcomes for high risk surgical procedures.\textsuperscript{128} Individual surgeon volume is also a predictor of the quality of certain procedures, such as radical prostatectomy. The conclusion drawn from this evidence is that centralising healthcare may yield better outcomes for patients urologic cancer surgery.

The respective volumes of providers of prostatectomy and bladder resections in London in 2007/08 are shown in figures 22 and 23.

\textsuperscript{125} Ibid.
\textsuperscript{126} NICE, Improving outcomes in urological cancers: the manual, 2002
\textsuperscript{127} Ibid.
\textsuperscript{128} FN Joudi & BR Konety, ‘The volume/outcome relationship in urologic cancer surgery’, Supportive Cancer Therapy, 2004, 2/1(42-6), 1543-2912
Figure 22: Number of prostatectomies carried out by London provider, 2007/08

Number of procedures

- Designated centre
- Provider undertaking five or less procedures per annum

*NW LH is no longer a separate multidisciplinary team due to merger with ICH but is authorised to undertake prostatic surgery.

Thirteen providers carried out prostatectomies in London in 2007/08. The picture for bladder cancer is similar, with 14 providers carrying out cystectomies. Some providers are clearly working with a catchment population considerably smaller than the recommended one million.

There are a number of London providers seeing a low volume of bladder and prostate cancer patients. Eight providers of prostatectomy carried out less than 50 procedures in 2007/08. All 14 of the providers carrying out cystectomies performed less than 40 procedures in 2007/08. Given the link between surgical volumes and patient outcomes, it is clear that Londoners are not currently being provided the world-class service they deserve.

**Drivers for change**

Since the publication of NICE guidance, clinical consensus has shifted away from radical surgery for prostate cancer. Preferred treatment options are now monitoring, radiotherapy and brachytherapy (also called internal beam therapy). Brachytherapy allows a physician to use a higher dose of radiation to treat a smaller area in a shorter time by placing a radioactive material directly next to the tumour. This practice has led to reduced surgical volumes. Recent peer reviews of urological
cancers indicated some London consultants are undertaking less than six operations per year.

Robotic prostatectomy is also being introduced but a sizeable catchment population is required to make this technology cost-effective, and it has not yet proven to produce better outcomes for patients.

**Key message**

There are a number of providers seeing a low volume of bladder and prostate cancer patients in London.

### 4.1.5 Haematological cancers

Haematological cancers (cancer of blood cells) represent the fifth most common type of cancer in the UK, accounting for seven per cent of all cancers.\(^{129}\) Haematological cancers are divided into three main diseases: leukaemia, lymphoma, and myeloma.

The NICE IOG recommends that:\(^{130}\)

- All patients with haematological cancer should be managed by multidisciplinary haemato-oncology teams serving populations of 500,000 or more.
- Every diagnosis of possible haematological malignancy should be reviewed and interpreted by experts who work with local haemato-oncology multidisciplinary teams and provide a specialised service at network level. This is most easily achieved by locating all specialist haemato-pathology diagnostic services in a single laboratory.

The British Society for Haematology is in the process of producing an updated detailed specification of the standards needed in the care of patients with haematological cancers. The guidance is intended for providers of clinical care and those who commission it.

### 4.1.6 Skin cancers

Skin cancer covers a number of tumour types, ranging from common to rare in their incidence. Common presentations such as precancerous skin lesions and low risk basal cell carcinomas can be managed in primary care, where appropriate, with rarer tumours such as malignant melanoma managed in specialist centres. The NICE IOG on skin tumours recommends how services for people with skin cancer should be organised:\(^{131}\)

- Cancer networks should establish two levels of multidisciplinary teams to care for patients, local multidisciplinary teams and specialist multidisciplinary teams.

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\(^{129}\) NICE, *Improving Outcomes in Haematological Cancers*, 2003  
\(^{130}\) NICE, *Improving Outcomes in Haematological Cancers*, 2003  
\(^{131}\) NICE, *Improving Outcomes for People with Skin Tumours including Melanoma: the Manual*, 2006
• Patients with a precancerous lesion should be treated by their GP or referred for diagnosis, treatment and follow-up to doctors working in the community who are members of the local or specialist multidisciplinary teams.

• Patients with low risk basal cell carcinoma should be diagnosed, treated and followed up by doctors working in the community as part of the local or specialist multidisciplinary team (usually a GP with a special interest in dermatology), or by a local hospital skin cancer specialist.

• All patients with a suspicious pigmented skin lesion, with a skin lesion that may be a high-risk basal cell carcinoma, a squamous cell carcinoma, or a malignant melanoma, or where the diagnosis is uncertain, should be referred to a doctor trained in the specialist diagnosis of skin malignancy.

The skin tumour IOG was published in 2006 and the first London peer review results will be available in March 2010. This will be the first peer review process to incorporate GP practices with the management of some cases taking place in primary care.

There is an emerging issue of some GPs diagnosing and managing low risk basal cell carcinomas when they are not adequately trained. A review of the IOG conducted in April 2009 concluded that the guidance warrants an update relating to the management of low risk basal cell carcinoma in the community. This updated guidance will be followed by a period of consultation on new peer review measures.

4.2 Bed days

A Framework for Action stated that one of the major ways to achieve good value care is to ensure people are not staying in hospital longer than necessary.\textsuperscript{132} Around 800,000 unnecessary bed days would have been saved if all London hospitals had achieved the national average length of stay in 2004/05 – equating to over £200 million.

The Cancer Reform Strategy showed England had higher hospital bed use for cancer than comparable countries, and bed occupancy accounted for a large proportion of cancer expenditure.\textsuperscript{133} The strategy also stated that over 14,000 cancer patients were in hospital at any one time. Non-elective admissions accounted for 60% of beds occupied and inpatient care for cancer patients accounted for 12% of all bed days. The strategy estimated 20-25% of cancer bed use (elective and non-elective) could be saved.

There is clear potential for London’s NHS to address the length of time cancer patients spend in hospital to improve the patient experience. There is scope for radical improvement in the use of London’s elective and non-elective cancer beds. Addressing some of the issues regarding late presentation and community care services will help reduce lengths of stay. Of London’s 31 PCTs, 10 are in the higher (worst) quartile when compared with the national average for elective bed days. For

\textsuperscript{133} Department of Health, \textit{Cancer Reform Strategy}, 2007
non-elective bed days, 19 London PCTs are in the higher quartile and 16 are in the higher quartile for emergency average length of stay.\textsuperscript{134}

At the same time, it is also important to have regard for the appropriateness of the home environment, and the preparedness of primary and community care to receive a discharged patient into a satisfactory level of care.

4.2.1 Elective bed days

There is considerable variation in the amount of time patients spend in hospital after elective surgery. Figure 24 shows the mean post-operative length of stay following a colectomy for each provider. It is clear there is considerable variation in the post-operative length of stay for this procedure across London. Patients in the best performing providers stay less than eight days whereas the worst performers keep patients in hospital for over 16 days.

The variation in performance is due to different surgical practices being used across London. Variation in surgical techniques and the use of day case surgery affects a patient’s speed of recovery. There is also variation in discharge practices and community support, which allows patients to be discharged when they no longer need to be in hospital.

Enhanced recovery is a series of measures to improve and shorten the recovery period following medical intervention. Programmes of enhanced recovery for patients

\textsuperscript{134} Department of Health, \textit{Cancer in London: A national perspective}, Professor Mike Richards, November 2009
involve changing the management at all stages of the patient pathway and have been successfully piloted, and should now be implemented across London’s cancer care providers.

A recent study found patients undergoing colorectal resection with an enhanced recovery programme stayed in hospital half as long as those receiving conventional care.\textsuperscript{135} Other advantages include reduced costs, and enhanced patient safety and satisfaction.

**Case study: Enhanced Recovery after Surgery\textsuperscript{136}**

One London provider worked with NHS Improvement to improve the quality of patient care and reduce the length of stay in colorectal cancer patients by introducing an Enhanced Recovery after Surgery (ERAS) integrated care pathway.

Before the project, the provider’s average post-operative length of stay was 16.6 days, 6.3 of which were in the intensive therapy unit. The ERAS pathway project served to reduce the provider’s average length of stay by more than half to 8.2 days.

**Key message**

There are significant variations in post-operative length of stay across London. Variations could be addressed by standardising surgical techniques and discharge practices, and increasing the use of day surgery.

### 4.2.2 Non-elective admissions

“My friend] had to be admitted back to hospital a number of times as an emergency. The experience of having to do this via the A&E Department was lengthy, bureaucratic and distressing.”

**Patient panel member**

Non-elective cancer admissions occur for two reasons: the presentation of symptomatic patients with undiagnosed cancer and the presentation of diagnosed patients experiencing adverse reactions to treatment, such as systemic anti-cancer therapy.

The case for ensuring earlier diagnosis of cancer in London has already been made. Early detection will not prevent all presentations of undiagnosed patients and


emergency departments in London will continue to see these patients, as well as those experiencing adverse reactions to treatment.

The NCAG report recommends all providers with emergency departments develop an acute oncology service to ensure patients admitted non-electively are seen by specialists. This initial specialist assessment may result in no admission or prevent admission to non-specialist units, and potentially poor care and a longer hospital stay. In addition, an impact assessment of the NCAG report has found that implementation will be cost neutral because the improved quality of treatment will reduce the number of emergency bed days.

At present, not all emergency departments in London have acute oncology services and therefore patients are not always seen by appropriate professionals and may be admitted to general wards.

One of the key recommendations of the NCAG report is to assess patients before admitting them to hospital. This includes providing patients with access to advice 24 hours a day, seven days a week. Clinicians staffing these advice services should have access to outpatient information for the population they are serving. This will prevent patients defaulting to emergency admission. Patients and carers should also be given information and advice about complications that may arise.

Cancer of unknown primary

Cancer of unknown primary origin is the diagnosis when metastatic cancer is found but the place where the cancer began (the primary site) cannot be determined. Patients diagnosed with possible malignancy of unknown primary, through primary care or radiology departments, are often admitted to general wards where they undergo numerous investigations in an attempt to achieve a diagnosis. Some of these investigations are unnecessary and this with the lack of timely assessment by a specialist result in a prolonged stay in hospital.

The acute oncology pilots currently running have sought to incorporate the unknown primary pathway into the work of the acute oncology team to improve the services offered to these patients.

Case study: Acute oncology and unknown primary pathways

One London hospital’s acute oncology pilot provides urgent review (in 24 hours) from Monday to Friday; admission to the specialist cancer ward for known cancer patients; and a fast-track clinic for patients with undiagnosed suspected cancer. This is supported by a rapid alert patient admission system to identify known cancer patients who are admitted with toxicity or complications secondary to their disease or treatment.

The unknown primary pathway is a core function of the acute oncology team. Early results show a reduction in unnecessary investigations, reduced length of stay, and reduced delays in onward referral to an appropriate team.

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137 NHS Improvement, *Transforming care for cancer inpatients: spreading the winning principles and good practice*, 2009
Key message

There is scope for radical improvement in the use of London’s elective and non-elective cancer beds.

All London providers with emergency departments should develop an acute oncology service, in line with NCAG recommendations.

4.3 Systemic anti-cancer therapy

Systemic anti-cancer therapy is used to kill cancer cells or prevent them from multiplying and may be used before or after surgery and/or radiotherapy. Systemic anti-cancer therapy may be administered by injection or orally and includes chemotherapy medicines with direct anti-tumour activity, in addition to targeted therapies and hormonal treatments.

A wide variety of systemic anti-cancer therapies are currently available and any one particular regimen may consist of a combination of several medicines, used together with supportive medicines, to manage the toxicities of the treatment or the disease. Each regimen will be tailored to the specific type of cancer being treated. The decision to treat an individual patient with systemic anti-cancer therapy will be made at a multidisciplinary team meeting, on a case by case basis.

4.3.1 Quality and safety

The use of systemic anti-cancer therapy has expanded markedly in recent years and while this has brought benefits to patients, serious concerns have been raised about the quality and safety of treatments.

An enquiry into the care of a number of patients who died in 30 days of receiving systemic treatments in June and July 2006 found only 35% of cases had good care, half had room for improvement, and eight per cent had less than satisfactory care.138

The enquiry also found that 42% of those patients were admitted to general medical care following a treatment complication rather than an oncology specialist.

In response to this report, the 2009 NCAG report identified a need to extend the availability of emergency assessment and treatment for cancer patients suffering side effects from systemic treatments, as well as fast-track assessment for suspected cancer patients needing emergency care.139

‘In many places, PCTs contract directly with individual hospitals, but this arrangement does not help support integrated chemotherapy service provision across providers and may actively work to fragment patient care.

138 National Confidential Enquiry into Patient Outcome and Death, For Better or for Worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy, 2008
139 National Chemotherapy Advisory Group, Chemotherapy Services in England: Ensuring quality and safety, 2009
'Many of the problems identified by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) relate to breakdown in communications across providers, with patients’ records not being available when they need emergency treatment at different hospitals in the Network.

‘PCTs in the Cancer Networks will need to consider how they can collectively commission an integrated network of chemotherapy/Acute Oncology Service provision, supported by integrated chemotherapy information systems.\textsuperscript{140}

The NCAG report concluded that all hospitals with emergency departments should establish an acute oncology service, which brings together necessary expertise from emergency medicine, general medicine and oncology.\textsuperscript{141}

**Key message**

Best practice guidance to improve the quality and safety of systemic anti-cancer therapy should be implemented across London.

4.3.2 Service delivery

“Obviously [a major] negative [is] the travelling for treatment and how tiring this is; waiting too long to see people; [and] not knowing who is the right person to talk to about certain aspects of the treatment.”

*Patient panel member*

The 2009 NCAG report recommended inpatient delivery of systemic anti-cancer therapy should be minimised and services should be provided closer to a patient’s home, where clinically appropriate.

Systemic anti-cancer therapy in London is provided predominantly in acute hospitals. It is often a standard treatment that does not necessarily need to take place in a hospital. As a result, patients are required to travel further for treatment, often when feeling unwell.

An appropriate balance between centralisation and localisation is needed to ensure all services are safe, effective and in line with the NCAG guidance.

Evidence confirms that certain aspects of cancer care can be delivered in the community and this can also lead to improved patient experience. A UK study reported that home systemic anti-cancer therapy was an acceptable and safe alternative to

\textsuperscript{140} Ibid.

\textsuperscript{141} NCAG made numerous other recommendations to improve the quality of chemotherapy and acute oncology services which require implementation across London.
hospital treatment for patients with colorectal cancer, and that it may improve compliance and satisfaction with treatment.\textsuperscript{142}

At present, there is a lack of an IT infrastructure in London to support a quality systemic anti-cancer therapy service.

“One thing that I felt was really fantastic when I was having chemotherapy was that there was a 24-hour hotline. I could ring at any time and speak to a chemotherapy nurse. One of the nurses from the unit always had the mobile and was available to talk if you were uncertain or needed to know anything. To talk to a sympathetic and knowledgeable person was invaluable.”

Patient panel member

Key message

The concentration of systemic anti-cancer therapy services in London results in patients frequently having to travel and with considerable travel times for their course of treatments when often feeling unwell.

There is a lack of an IT infrastructure in London to support a quality systemic anti-cancer therapy service.

4.3.3 New drugs

Development of new hormonal and anti-cancer treatments targeted at specific molecular abnormalities and the increasing use of drugs has improved the treatment of cancer over recent years. All Londoners should have equal access to clinically appropriate and cost-effective treatments.

NICE guidance ensures this, although there are concerns about the time this process can take and the need for PCTs to make decisions when guidance is not available. The London Cancer New Drugs Group is recognised\textsuperscript{143} as a valuable source of information to help PCTs make decisions about new interventions. The group’s reviews are clinically robust and developed with input of specialist clinicians. As part of its work the group also undertakes a horizon scanning and new drug prioritisation process on behalf of PCTs.

\textsuperscript{142} JM Boras, A Sanchez-Hernandez, M Navarro, et al, Compliance, satisfaction, and quality of life of patients with colorectal cancer receiving home chemotherapy or outpatient treatment: a randomised controlled trial, 2001

\textsuperscript{143} Health Services Circular, Good Practice Guidance on Managing the Introduction of New Healthcare Interventions and Links to NICE Technology Appraisal Guidance, 2006
“[A key challenge is to]... strengthen the role of the London New Cancer Drugs Group in commissioning new cancer treatments not yet considered by NICE.”

General practitioner

Key message

Collaborative commissioning is required to prioritise new cancer drugs. The London Cancer New Drugs Group recommendations to ensure equity across London have not yet been implemented.

4.4 Radiotherapy

Radiotherapy is the use of high energy rays to kill cancer cells. Unlike chemotherapy, radiotherapy is a local treatment that affects only those cancer cells directly in the treated area. Radiotherapy can be delivered externally by machine, or internally (brachytherapy) where radioactive material is placed in the body near cancer cells.

Radiotherapy contributes to a cure in circa 40% of cancer cases (either on its own or in combination with other treatments). It is vital that London has a world-class radiotherapy service. New technologies to deliver this service are set out in section 5.9 (specialist treatments) and apply to the treatment of a range of both common and rare cancers.

The National Radiotherapy Advisory Group (NRAG) was asked to advise the Government on the position of radiotherapy services in England. Its report, published in 2007, outlined how to ensure current resources are deployed to best effect and how to plan for a world-class service in the longer term.144 The London Cancer Network Board comprehensively assessed the implications of the NRAG report for London in its report of 2009.145

Both reports point to a general consensus that the projected need for radiotherapy has been underestimated and is set to worsen as cancer incidence increases. However, the Board concluded that London providers have enough linear accelerators (linacs) to be able to deliver appropriate treatment for all patients requiring radiotherapy, if they are adequately staffed and used efficiently. The London Cancer Network Board identified issues that need to be addressed to ensure this can be achieved.

According to NRAG modelling about 52% of cancer patients should receive radiotherapy at least once during the course of their illness. There is variation in the proportion of patients who are receiving radiotherapy across London networks. Data from the London Cancer Network Board report suggests that 34-42% of patients

receive radiotherapy, depending on the network. Agreement across all London networks on referral for radiotherapy treatment is required to address this issue.

There are variations among providers on the fractionation regimen given to patients, particularly for breast, prostate, and lung cancers when compared with the NRAG recommended fractions.

Furthermore, the London Assembly reported that waiting times in a third of London’s trusts exceed national waiting time targets.\textsuperscript{146} London-specific factors exacerbating national problems include problems retaining staff due to the cost of living, varying workloads, commissioning relationships between PCTs and acute trusts, and the fragmented management of the radiotherapy service.

The London Cancer Network Board concluded that consideration of centralised commissioning of radiotherapy by the specialist commissioning group for London would ensure patient flows are managed across the capital. The NRAG report suggested a more dispersed model of services to reduce patient travel times but one that avoids the possible workforce issues that fragmentation of services could create.

Radiotherapy is currently delivered at eight NHS trusts in London, and treatment is also delivered for Londoners at Mount Vernon Cancer Centre in Hertfordshire. There are also three private providers of radiotherapy in London. Private providers are not routinely commissioned to provide radiotherapy for NHS patients.

London’s radiotherapy providers are set out in figure 25.

\textsuperscript{146} The London Assembly - Health and Public Services Committee, \textit{Behind the Screen: Breast Screening Uptake and Radiotherapy waiting times in London}, March 2008
The London Cancer Network Board report showed that 19.5% of patients in the south east London cancer network region travel more than 10 miles to receive treatment. For other London networks the percentage of patients travelling more than 10 miles ranges from 0.4% to 4.2%, although the latter figure reflects the extension of the north London network into west Essex. This large variability is unsatisfactory for many London patients.

The south east London cancer network is developing plans to improve equality of access in the network. Opportunities for delivering services at new units, following any planned decommissioning should be considered early, and take into account improving patient access to radiotherapy treatment.

**Key messages**

Consideration of centralised commissioning of radiotherapy may ensure patient flows are managed more efficiently across London and that safety and quality standards are met.

Opportunities for placing the delivery of services on new sites following any planned decommissioning should be considered early and take into account improving patient access to their radiotherapy treatment.

There is variation across London networks on fractionation regimes for treating cancers.
4.5 Multidisciplinary teams

“Multidisciplinary working must be enhanced. Surgeons, Clinical Oncologists and Medical Oncologists must work more effectively in teams so their individual strengths and expertise are maximised.”

Consultant clinical oncologist

The multidisciplinary team is a team of specialist practitioners, who discuss and determine the best treatment care pathway for individual patients.

Multidisciplinary teams deal specifically with one type of cancer or group of cancers. Members come from relevant professions with specialised knowledge of diagnosis and treatment, including surgeons, radiologists, pathologists, oncologists, nurse specialists, palliative care specialists, allied health professionals and coordinators. A team may cover more than one hospital if numbers of patients treated are low in particular locations.

NICE guidance stipulates the parameters and requirements for multidisciplinary teams. For example:

- The guidance for colorectal cancer states that a separate multidisciplinary team must exist for anal cancer and it must be hosted at a unit delivering radiotherapy.

- The guidance for lung cancer states that thoracic surgical presence is required at all lung cancer multidisciplinary team meetings to allow the identification of patients appropriate for surgery.

- The guidance for haematology states that multidisciplinary teams should serve populations of 500,000 or more.

NICE specifications for multidisciplinary teams are not fully implemented across all providers of cancer care across the capital.

Data on the compliance of multidisciplinary teams with NICE guidance are available through the National Cancer Peer Review Programme. The 2004-2007 review, and subsequent reports on progress of remedial action, reveal a significant number of multidisciplinary teams were not compliant with peer review measures. 147 The latest London peer review is underway and initial findings highlight the lack of standardised team structure, function and defined roles.

There is an increasing feeling among specialists that the multidisciplinary team meetings consume considerable amounts of time from busy consultants, whose contributions are not required for determining the best care management plans for

many patients being presented and discussed. This is considered an inefficient use of their clinical time and merits future thought.

Data on the precise membership of London’s multidisciplinary teams are not readily available. The evidence for the assertion that London has too many providers of common cancer surgery suggests multidisciplinary teams, site specific as they are, might also be too numerous. The 2004-2007 summary London peer review report showed there were gaps in the required core membership in a number of types of multidisciplinary teams, with thoracic surgery, histopathology and oncology the most common deficiencies.\textsuperscript{148} A significant number of teams were reliant on a single cancer nurse specialist and the range of surgical expertise present in different teams also varied widely.

Multidisciplinary teams also varied widely in how established the keyworker had become. The Manual of Cancer Services recommends multidisciplinary team operational policy should include identifying and recording in their case notes, a single named keyworker for the patient’s care.\textsuperscript{149}

Effective video conferencing and other technologies for successful team working should be explored. The use of electronic recording of multidisciplinary team discussions, such as eMDT – a web-based tool currently being piloted to coordinate team meetings and improve the availability of patient information, would also help facilitate inter hospital transfer of information.

\textbf{Key messages}

IOGs are not fully implemented. Fewer, larger multidisciplinary teams could ensure this if they are properly supported and contain all of the necessary specialist skills.

Effective video conferencing and other technologies are not available to all multidisciplinary teams across London.

\section*{4.6 Follow-up and support}

Improving survival rates for cancer patients means there are more long-term survivors. Long-term survivors have their own needs and will place an increasing demand on NHS services.

There are currently over eight million outpatient appointments for cancer patients in London each year.\textsuperscript{150} Not all of this outpatient care is necessary with evidence showing many of these appointments could be done by GPs and nurses.\textsuperscript{151}

The Cancer Reform Strategy effectively summarises the issues surrounding follow-up with the example of breast cancer:

\textsuperscript{149} Department of Health, \textit{Manual for Cancer Services}, 2004
\textsuperscript{151} National Primary Care Research and Development Centre, \textit{Can Primary care reform reduce demand on hospital outpatient departments?}, 2007
‘Standard practice after potentially curative surgery for breast cancer is regular hospital follow-up visits. The value of this resource intensive practice is constantly being questioned. It is acknowledged that routine hospital visits cause significant stress to the patient and, more importantly, most symptoms attributable to local recurrence are first identified by the patient.

‘Many clinicians believe that time spent following up essentially well women is not clinically beneficial or cost effective. Inevitably these routine visits lengthen waiting times for new referrals and may compromise the efficiency of individual diagnostic services.’\textsuperscript{152}

\textbf{“My sister built up a positive relationship with the consultant but five years after the treatment she finds going to [the outpatient centre] not useful as it reminds her of the trauma. She wonders if [follow up] test results could not be conveyed by phone or email.”}

\textsuperscript{152} Department of Health, \textit{Cancer Reform Strategy}, 2007

\textsuperscript{153} Fialka-Moser et al., \textit{Cancer Rehabilitation: Particularly With Aspects On Physical Impairments}, 2003

**Key message**

Specialists spend considerable time on unnecessary follow-ups in secondary and tertiary care. Freeing up these resources could enable wider improvements to the quality of care across the capital.

4.6.1 Rehabilitation

Increasingly the emphasis in cancer care is not simply on improving survival rates but on cancer rehabilitation, which aims to improve functional status, quality of life, and assisting patients to adapt to their condition regardless of where they are on their pathway.\textsuperscript{153}

The evidence reviews for NICE IOGs provide support for the inclusion of rehabilitation professionals in multidisciplinary teams, either as core or extended team members, because of their impact upon patient outcomes.

A national project is currently reviewing the rehabilitation input into tumour pathways and several symptom pathways. The five London cancer networks contributed to the national allied health professional (AHP) scoping exercise in 2008 to identify specialist cancer rehabilitation professionals. It showed a threefold difference in staffing between the lowest and highest staffed networks. This disparity did not reflect patient throughput.

Rehabilitation for cancer patients is highlighted in the supportive and palliative care IOG and specific reference to the role of the AHP in the site specific IOGs is also

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\textsuperscript{152} Department of Health, \textit{Cancer Reform Strategy}, 2007

\textsuperscript{153} Fialka-Moser et al., \textit{Cancer Rehabilitation: Particularly With Aspects On Physical Impairments}, 2003
made, with particular emphasis on head and neck, upper gastrointestinal, and brain and central nervous system (CNS) cancers.

NICE guidance on the role of rehabilitation in the cancer pathways, set out in the IOGs, has not yet been implemented across London but work has started on the development of local support teams for head and neck, and brain and CNS teams.

**Key message**

There are disparities between staffing of cancer rehabilitation professionals and workload across London, where specialist presence does not reflect patient throughput. This results in unequal access to these professionals.

NICE guidance on the role of supportive and palliative care has not been fully implemented across London.

### 4.6.2 Supportive and palliative care

The IOG on supportive and palliative care has not yet been implemented in London.

The World Health Organisation defined palliative care as:

> ‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.’

All healthcare practitioners should understand the principles of palliative care and be able to deliver initial interventions, assess patient needs and make onward referrals to specialist services.

The NICE IOG for supportive and palliative care outlines the issues involved in the provision of effective palliation:

> ‘Patients’ needs for […] palliative care may not be met for several reasons. Services from which they might benefit may not be universally available. Even when services are available, patients’ needs may go unrecognised by professionals, who consequently do not offer referral. Poor inter-professional communication and coordination can lead to suboptimal care.’

Engagement with primary care, social care, and voluntary sector organisations is vital in the ongoing support of both patients and carers, and this is not currently happening in London. The IOG also makes recommendations about the provision of information, complementary therapies and bereavement care.

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154 World Health Organisation, 2002
155 NICE, *Improving Supportive and Palliative Care for Adults with Cancer*, 2004
4.6.3 Holistic assessment

NICE guidance recommends that assessment should be an ongoing process throughout the course of a patient’s illness. Structured assessments should be undertaken at each key point along the patient pathway, including at diagnosis, at each new episode of disease recurrence, and at the patient’s request.

Healthcare professionals undertaking the assessment should have an appropriate level of knowledge of the disease for the stage at which they are making the assessment, and be able to make referrals to the relevant supportive and specialist services based on the assessment. The role of the keyworker is vital in this process.

4.6.4 Psychological support services

It is recognised that psychological distress is common among cancer patients and their families. Patients benefit from, and should therefore have access to, a range of services to support them from diagnosis onwards.

General staff in all settings play a vital role in the psychological support of patients and should be equipped with the skills and knowledge to assess and prevent psychological distress. More specialist interventions should be provided by members of the cancer multidisciplinary team or specialist palliative care teams. The involvement of specialist social workers, counsellors, clinical psychologists and liaison psychiatry may be required for a small number of cancer patients.

Psychological care is an element of provision that patient groups frequently identify as an area of need, and a service mapping exercise undertaken in north east London also recorded qualitative information that indicated distress among staff who felt unable to meet those needs. Peer review measures for psychological support were published in draft format in October 2009 and are expected to be reviewed in 2011.

Key messages

NICE guidance on the role of supportive and palliative care needs to be implemented across the capital.

Some clinicians are unfamiliar with the principles underpinning the palliative approach to care. A holistic assessment will identify unmet needs leading to referral to a full range of support services.

4.6.5 Treatments used with palliative intent

All treatment modalities used in the management of cancer can be used with palliative intent. Patients should have access to appropriate interventions to maintain a good quality of life, relieve symptoms and prevent or reduce the speed of deterioration, even when the disease is considered incurable. The benefit of invasive interventions must be weighed against the burden to the patient. The NCAG report highlighted the need

\[^{156}\text{North East London Cancer Network, 2006}\]
for clinicians to make clear to patients the benefits and risks of chemotherapy in the late stages of the disease.

**Key message**

Not all Londoners have timely access to interventions and treatments used with palliative intent across the disease pathway.

4.7 **Section summary**

Specific guidance exists on all aspects of general cancer services, as well as IOGs for each common cancer type. This section described how much of this guidance is not yet implemented in London. By implementing this guidance, the resulting efficiencies gained from a more coordinated and streamlined service would enable investment in primary care services and other areas of the patient care pathway.
5. Rarer cancers and specialist care

Rarer cancers and specialist services were defined for this project based on consultation with clinicians and London’s projected incidence rates – those with a predicted incidence in 2020 of less than 1,000 per million, as shown in Figure 26. The following types of cancers and treatments are considered rarer cancers for this project:

- upper gastrointestinal: oesophago-gastric tumours (OGT), hepato-pancreato-biliary (HPB) tumours, and hepatocellular carcinoma (HCC)
- urological: testicular, penile, and renal tumours
- head and neck tumours and endocrine tumours
- brain and CNS tumours
- gynaecological: ovarian, endometrial, cervical, vulval, and vaginal tumours
- sarcoma
- specialist treatments: haematopoietic progenitor cell transplantation (HPCT), molecular diagnostics, specialist imaging and specialist radiotherapy.

The list is not intended to be exhaustive. The most common types of rare tumours are set out whereby the service issues are generally applicable to the management of rarer cancers. Incidence rates for rare tumour types are presented in figure 26.

Figure 26: Predicted rare cancer incidence in London 2001-2020\textsuperscript{157} per million population

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Incidence 2001</th>
<th>Incidence 2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lip, mouth, pharynx</td>
<td>554</td>
<td>849</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>668</td>
<td>834</td>
</tr>
<tr>
<td>Stomach</td>
<td>835</td>
<td>723</td>
</tr>
<tr>
<td>Pancreas</td>
<td>754</td>
<td>847</td>
</tr>
<tr>
<td>Cervical</td>
<td>294</td>
<td>235</td>
</tr>
<tr>
<td>Endometrial</td>
<td>535</td>
<td>674</td>
</tr>
<tr>
<td>Ovary</td>
<td>641</td>
<td>634</td>
</tr>
<tr>
<td>Testicular</td>
<td>199</td>
<td>221</td>
</tr>
</tbody>
</table>

For some rare cancers, several London hospitals are providing services for the relatively small number of cases in the capital. This section presents the case that surgical outcomes (peri-operative mortality), survival rates, and quality of care can be improved if specialised services are concentrated in fewer centres.

For each rare cancer type, other aspects of the patient care pathway and specialist multidisciplinary team structure where there is a case for service improvement, centralisation, or collocation are also outlined.

### 5.1 Meeting national guidance

“A key challenge for London is to address the fragmentation of specialised cancer services.”

*Upper gastrointestinal consultant surgeon*

Most NICE IOGs for rare cancer set out minimum volume population catchments to underpin the clinical quality standards required. The guidance also argues that each surgical team needs to see a minimum number of patients to preserve its clinical skills.

For surgeons, this not only relates to managing patients by procedures undertaken but also to assessing patients for surgery and managing complications. If the numbers of patients per surgeon in any of these areas is low, lack of experience may result in poorer outcomes. This is also the case for oncologists and other specialist multidisciplinary team staff. While IOGs do not set out minimum volumes for non-surgical oncology, minimum population catchments for specialist multidisciplinary teams indicate that specialisation is encouraged to improve outcomes.

Peer review shows certain procedures have become concentrated in the hands of a smaller number of surgeons while others continue to challenge the typical IOG compliant model. However, the intention of the NICE IOGs and the clinical driver to further reorganise services, is not only the provision of minimum volume requirements, but the improvements to service infrastructure that underpin specialist centres. In other words, London services need to consider optimal populations not just minimum populations.

For some rare cancers, co-dependencies with specialist support services and intensive care units exist. National guidance shows the concentration of cases can achieve both a critical mass of talent and financial sustainability.

### Key messages
Peer reviews show certain procedures are concentrated with a small number of surgeons while others continue to challenge the typical IOG compliant model in London.

Concentration of cases can achieve both a critical mass of talent and financial sustainability. Achieving minimum volumes is not enough.

5.2 Improving quality and outcomes

There is strong evidence to suggest peri-operative mortality and long-term survival worsen as hospital surgical volume decreases.\(^{158}\)

Numerous studies in recent decades have examined the relationship between high volume hospitals, long-term survival and peri-operative mortality, including for complex cancer services.\(^{159,160}\)

The following studies demonstrate high volume hospitals have better outcomes for major cancer resections and other high risk procedures:

- A recently published study scrutinised 135 published studies covering a range of 27 surgical procedures or clinical conditions, and looked at both hospital volume and doctor/surgeon volume for the condition studied.\(^{161}\) The report concluded that most of these studies highlighted a direct relationship between volumes and improved outcomes. This was most marked in complex or high risk procedures, such as complex surgery and cancer treatment.

- A US literature review of urological cancer surgery concluded higher hospital volume is associated with better outcomes.\(^{162}\)

- A systematic review evidenced an inverse relationship between hospital surgical volume and mortality.\(^{163}\) In five evaluations in a decade, hospital mortality rates were between 13.8% and 16.5% in hospitals with less than five pancreatic resections per year. However, hospital mortality rates were between zero and 3.5% in hospitals with more than 24 pancreatic resections per year.

- A review of provider volumes and outcomes for cancer procedures in the UK undertaken in 2005 found that high volume providers had significantly better

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outcomes for complex cancer surgery, particularly pancreatectomy, oesophagectomy, gastrectomy and rectal resection.\textsuperscript{164}

Technological advances are also driving more centralisation of specialist services. The most complex cases require a range of diagnostic and treatment equipment to be available in one place. This would require locating high technology equipment in centres of expertise with sufficient concentrations of experienced trained staff, and where there are enough cases, to justify the technology’s cost.\textsuperscript{165}

\begin{flushleft}
\textbf{Key message}

There is evidence that worse clinical outcomes are associated with low volumes.
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5.2.1 Specialist expertise

Surgeons and their teams who see more of a particular diagnosis or perform a greater number of specific procedures, for rare and common cancers, typically achieve higher quality outcomes.\textsuperscript{166,167,168} For example, the association between higher surgeon volume and better outcomes from surgeons undertaking oesophagectomies has been highlighted in the \textit{Cancer Reform Strategy}\textsuperscript{169} where between 1997 and 2005, surgeons undertaking these procedures reduced from 309 surgeons in 147 trusts to 188 surgeons in 96 trusts. There was an average 1.5 fold increase in the number of such operations per trust and per surgeon. The number of patients that died in hospital following one of these operations almost halved in this period (from 9.4\% to 4.9\%).

A US review\textsuperscript{170} reported differences in mortality rates of 10\% when high volume units were compared to low volume units for a number of complex high risk surgical procedures, including pancreatic cancer surgery and oesophageal cancer surgery as set out in figure 27.

\begin{flushright}
\footnotesize
\textsuperscript{166} BE Hillner, TJ Smith & CE Desch, \textit{Hospital and physician volume or specialization and outcomes in cancer treatment: importance in quality of cancer care}, 2000
\textsuperscript{167} FN Joudi & BR Konety, ‘The Volume/Outcome Relationship in Urologic Cancer Services’, \textit{Supportive Cancer Therapy}, October 2004, 2/1(42-6), 1543-2912
\textsuperscript{169} Department of Health, \textit{Cancer Reform Strategy}, 2007
\end{flushright}
Peer review shows certain procedures have become concentrated in the hands of a smaller number of surgeons. The ongoing drivers to improve the quality of care described in previous sections are dictating a further consolidation of services, surpassing the argument of volume advantages towards maintaining a clinical environment that delivers best practice.

Volume is only one of a number of factors. Other factors include training and experience, complementary surgical teams, hospital resources, organisation and processes of care can also influence outcomes. It is fundamental that specialist services are available and delivered by appropriately qualified teams with sufficient practice to maintain their skills and sustain expertise. Centralisation of specialist cancer services will provide a means of consolidating scarce specialist expertise to improve clinical quality. Such concentration of care, with large numbers of patients, creates centres of excellence and supports training to ensure cover is provided to release staff for training and to comply with the European Working Time Directive.

**Case study: Cancer Care Ontario**

An example of the combined benefits of centralisation is in Ontario, where Cancer Care Ontario undertook a regionalisation programme for major pancreatic cancer surgery. Changes included surgeon training, hospital resources, and public reporting of mortality data. The provincial mortality rate from major pancreatic cancer surgery

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has decreased by more than half since the introduction of the programme.

5.2.2 High performing specialist multidisciplinary teams

Section 4 set out the benefits of creating fewer, larger multidisciplinary teams that are properly supported and contain all the necessary specialist skills for all cancer types. Specialist multidisciplinary teams are teams that provide services for complex cancer cases.

To consolidate scarce specialist expertise and improve clinical quality, the caseloads of specialist multidisciplinary teams in London need to be reviewed to assess whether they provide a full range of treatments, and at what frequency. Specialist multidisciplinary teams are not currently organised or resourced in a way that maximises the number of patients seen.

Whole pathway management is particularly difficult in rare cancers because the link between GP and specialist provision is geographically and procedurally stretched. An important role of the specialist multidisciplinary team is to link back to the local multidisciplinary team where it is appropriate for adjuvant treatment, such as chemotherapy or radiotherapy, to be delivered locally for ease of access for patients.

Section 4 set out the importance of communication for successful multidisciplinary team working. Managing the delivery of care plans of patients are constrained by organisational boundaries in London.

**Key message**

The ongoing drivers to improve the quality of cancer care are dictating a further consolidation of services, surpassing the simplistic argument of volume advantages towards maintaining a clinical environment that provides a platform for the delivery of best practice developments.

Specialist multidisciplinary teams are not currently organised or resourced in a way that maximises the number of patients seen by each. Managing the delivery of care plans of patients are constrained by organisational boundaries in London.

5.2.3 Volume to support audit of outcomes and to enhance research

Critical mass provides the basis for the meaningful audit of outcomes, which cannot be precisely measured in small volume services. A single specialist team and higher volumes will allow for better assessments of outcomes and, subsequently, more sophisticated outcome measures to enable benchmarking and international comparison. This would be achieved through recording data over time as systems are established and service infrastructure is developed.

Section 2 set out the benefits of having three AHSCs and other similar high quality research providers in London. Given the lower incidence of rare tumours, specialist and rare cancer services particularly benefit from research rich
environments. This would increase the opportunities for clinical cancer research through increase uptake into clinical trials and high quality translational research.

**Key message**

Planning for the delivery of specialist and rare cancer services on new sites should consider the improvements in cancer care that result from uptake to clinical trials and high quality translational research.

London services for individual rarer cancer types are set out below, in the context of the advantages of centralising specialist cancer services.

### 5.3 Upper gastrointestinal cancers

Cancers of the oesophagus, stomach, pancreas, and liver are referred to collectively as upper gastrointestinal cancers. Pancreatic services are usually part of HPB (hepato-pancreato-biliary) services, as the same specialists may deal with pancreatic and hepatic (liver) tumours. These cancers are rarely diagnosed until they reach an advanced stage and consequently the prognosis for most patients is poor (particularly for pancreatic cancer) with more than three quarters dying within a year of diagnosis.

#### 5.3.1 Oesophago-gastric (OG) cancer

The upper gastrointestinal cancers IOG\textsuperscript{172} stipulates that OG specialist multidisciplinary teams should serve populations of one to two million. The OG multidisciplinary team should be in a local hospital setting, collocated with a diagnostic service. The specialist multidisciplinary team should host a minimum of 100 OG resections per year.

Three of five cancer networks in London have undergone peer review. The reviews have evidenced a decline in surgical volumes, thus supporting an argument for fewer services.

Figure 28 shows that of the 13 named providers in London, seven of them (54\%) each performed less than 40 of the total of 569 oesophagectomies, gastrectomies and oesophagogastrectomies performed in 2007/08.

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Most providers have the minimum one million catchment population. Since the IOGs were published, research has found that improvements in imaging has led to a more accurate diagnosis regarding the spread of disease. Previously surgeons would operate and then determine disease spread. Imaging has led to a reduced number of resections by detecting inoperable cancers or diseases, which had already metastasised. As improvements in chemotherapy treatments become available, the primary treatment option will become a mix of chemotherapy and radiotherapy rather than surgery.

5.3.2 Pancreatic cancer

The upper gastrointestinal cancers IOG\textsuperscript{173} stipulates specialist multidisciplinary teams should serve populations of two to four million, preferably at the upper end of the

range. The guidance also sets out that specialist surgery should be based in a specialist setting, and specialist HPB surgeons should operate on patients with non-malignant disease, since malignancy may not be confirmed until after resection.

There is some centralisation of HPB services in some sectors but there is still a relatively small surgeon caseload. Figure 29 shows the number pancreatectomies undertaken by each of the London providers in 2007/08.

### 5.3.3 Hepatocellular carcinoma (HCC)

Cirrhosis and Hepatitis B are responsible for the overwhelming majority of cases of HCC in the UK. Surveillance (a screening modality) for HCC in at-risk groups has been recommended in best practice guidelines but the UK does not have a robust surveillance programme.

Management of HCC usually involves the parallel management of two diseases – the underlying cirrhosis and the malignant disease.
Consequently, it does not follow the traditional model of oncological care. The National Liver Plan\footnote{K Moore, M Thursz & DF Mirza, National Plan for Liver Services – Specialised Services for Hepatology, Hepatobiliary and Pancreatic Surgery, Report prepared for the British Association for the Study of the Liver, 2003} recommends patients are managed in centres that offer all treatment options (resection, liver transplantation, and loco-regional therapies) or have appropriate relationships to cover local deficiencies. The plan also stipulates that hepatologists are central to the multidisciplinary team.

**Key messages**

There are too many service providers for oesophago- gastric surgery in London. Improvements in diagnostic imaging have led to a reduced surgeon caseload.

There are too many service providers of HPB surgery in London and IOG minimum volumes are not currently being met.

5.4 Rarer urological cancers

Rare urological cancers include testicular, penile, and renal tumours. The majority of testicular and penile cancers are identified early and survival rates are high.\footnote{NICE, Improving Outcomes in Urological Cancers: The Manual, 2002, p 16-18} Of all testicular cancers, 95% are germ cell tumours. Germ cell tumours in men are classified as either seminomas or non-seminomas, which are related to treatment options and prognosis.

Renal cell cancer accounts for over 80% of kidney cancers. Early renal cancer produces no symptoms and is usually detected by ultrasound or CT scan. Treatment is primarily surgical as these types of cancers tend not to respond to chemotherapy.\footnote{NICE, op. cit. p 20-21}

5.4.1 Testicular cancer

The urology IOG stipulates that specialist multidisciplinary teams should serve populations exceeding two million, working at the supranetwork level. Surgeons and their teams are expected to treat 50-100 new patients a year and should liaise closely with local urological cancer teams.

There are urology multidisciplinary teams in each cancer network and three testicular centres in London. This configuration exceeds the minimum IOG requirement, as they are serving large catchment populations of between three and six million.

5.4.2 Penile cancer

Specialist multidisciplinary teams should serve populations exceeding four million, working at the supra-network level. Surgeons and their teams are expected to treat a minimum of 25 new patients a year.
There are two specialist centres in London and 10 nationally. This configuration exceeds the minimum IOG requirement, as the centres are servicing large catchment populations of seven and nine million.

For both testicular and penile tumours, attention needs to be given to consultant numbers at cancer centres because of the European Working Time Directive and dependencies on single surgeons for delivery. Improved communication between urology multidisciplinary teams and specialist urology multidisciplinary teams is required to ensure complex cases are referred to, and treated at, specialist centres.

5.4.3 Renal cancer

Service configurations for renal surgery in London are incorporated into urology multidisciplinary teams and specialist multidisciplinary teams. The use of laparoscopic and robotic techniques for radical nephrectomies (surgical procedure for kidney cancer) is increasing. However, patients are not always offered this when appropriate, as the framework for referral to specialist centres with appropriate expertise is not formalised in London.

Key messages

The current service configuration in London for rare urological cancers is appropriate.

Consultant numbers for specialist urological services and dependencies on single surgeons for delivery needs to be monitored.

5.5 Head and neck cancers

The majority of these cancers arise from the surface layers of the upper aerodigestive tract (UAT): the lip, mouth (oral cavity), the upper part of the throat and respiratory system (pharynx), and the voice-box (larynx). Other UAT areas include the salivary glands, nose, and sinuses, but these cancers are relatively rare. Cancers that originate in the connective tissues of the head and neck are even rarer.

Most patients with UAT cancers are middle-aged or older. Survival rates differ markedly according to the site and stage of the cancer.

Endocrine cancers arise from glandular tissues in the body that secrete hormones directly into the bloodstream. Thyroid cancer is the most common endocrine malignancy, although it is an uncommon cancer, comprising only about one per cent of invasive cancers. The primary treatment for thyroid cancer is surgery.

The head and neck cancers IOG\textsuperscript{177} stipulates that specialist multidisciplinary teams should serve populations exceeding one million. All surgery should be provided by a specialist multidisciplinary team in a designated centre, and surgeons and their teams should manage a minimum of 100 new cases of UAT cancer a year.

\textsuperscript{177} NICE, \textit{Improving Outcomes in Head and Neck Cancers}, 2004
This guidance stipulates that thyroid cancers should be managed either together with the UAT cancers or in an endocrine specialist multidisciplinary team. All patients with thyroid cancer, including those whose cancer is diagnosed during surgery for apparently benign disease, should be referred for management by thyroid cancer multidisciplinary teams.

Since thyroid cancer is a relatively rare condition with an incidence rate of roughly two patients per 100,000 population per year, these specialist multidisciplinary teams will also only be required in large centres (serving populations in excess of a million). Due to the small volume of cases per year, some London head and neck multidisciplinary teams manage patients with malignant thyroid tumours, while separate thyroid multidisciplinary teams manage benign cases. Other providers have their thyroid multidisciplinary teams managing patients with both malignant and non-malignant disease.

The specialist multidisciplinary team structure is well established. The provision of local, community-based rehabilitation teams for patients are in various stages of development and these must be equally provided and funded across London to meet IOG guidance.

Figure 30 shows that of the 26 UAT surgery providers in London, 19 (73%) performed 100 or less of the total of 1,321 surgical procedures performed in 2007/08. Figure 31 shows that of the 23 thyroid cancer surgery providers in London, 14 (61%) performed 10 or less of the total of 241 surgical procedures performed in 2007/08. However, the head and neck cancers IOG was only being implemented during 2009 and peer review visits have shown surgery has been concentrated to the designated centres.
Figure 30: Total number of upper aero-digestive tract procedures by London provider, 2007/08

Number of procedures

Designated centre

Provider undertaking five or less procedures per annum

*Provides paediatric services only.
**No longer undertaking UAT surgery.

There are benefits of being a reasonably centralised service, particularly due to the number of specialties involved (maxillofacial; ear, nose and throat; plastic surgeons; clinical oncologists; speech and language therapists; dieticians; restorative dentists; and clinical psychologists). In London there is a rationale for future consolidation given these complexities and the high level of specialist expertise required.

The IOG allows surgery to take place locally by surgeons designated by the multidisciplinary team. Increasing numbers of head and neck cancers are treated with chemotherapy and radiotherapy regimes as a primary or adjuvant treatment, and these will ideally be allocated. Service infrastructure needs to be improved to ensure high quality rehabilitation and aftercare services. Large volumes of benign disease surgery are also undertaken by multidisciplinary teams and care should be directed and designated by the specialist multidisciplinary team.

**Key message**

The process of implementing IOGs has progressed; however, there is scope for reconfiguration of head and neck services into a smaller number of larger centres.
5.6 Brain and central nervous system cancers

Although the prognosis for many patients with brain and CNS tumours has improved greatly in recent years, the outcome of patients with high grade gliomas, the most common primary brain tumour, remains poor with the median survival below 18 months. Less than one in 20 brain tumours (five per cent) are a primary CNS lymphoma. The group includes some extremely rare tumours of the spine, skull base and pituitary gland.

The brain and CNS cancers IOG covers both malignant and non-malignant tumours because of the impact on morbidity and mortality when tumours are located in the brain or CNS.

The risk of developing CNS tumours is dependent on age and gender. Tumours of the brain are also more common among more affluent groups, and this is also true for mortality. The reverse trend is evident for brain metastases.

The IOG acknowledges that because these cancers require specialist neurosurgery and oncology services, specialist multidisciplinary teams should be based in neuroscience and cancer centres and should be serving a minimum of 100 new patients per year. The IOG sets out a model of a neurosciences specialist multidisciplinary team, centred on neurosurgery, and a cancer network multidisciplinary team that will deal with subsequent oncological aspects of treatment pathways.

NICE clinical guidance on metastatic spinal cord compression (MSCC) recommends that each cancer network should have a clear care pathway for the diagnosis, treatment, rehabilitation and ongoing care of patients with MSCC.

There are seven neuroscience centres serving population catchments between one and four million. The current model is based on neurosciences centres working with cancer network multidisciplinary teams and local services to support post or non-surgical care.

Figure 32 shows that of the nine named providers in London, five (67%) performed less than 160 each of the 1,636 procedures performed in 2007/08. However, 2009 peer review visits have shown surgery has been concentrated to seven adult providers.

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178 NICE, Improving Outcomes for People with Brain and other CNS Tumours, 2006
179 NICE, Metastatic spinal cord compression: Diagnosis and management of patients at risk, 2008
Nationally, brain and CNS services support populations significantly larger than those served by some of the London neuroscience units. London needs to consider if the proposed configuration of services achieves an optimal population or if greater concentration of cancer-related work would deliver more sustainable and cost-effective teams.

Nationally, there is a need to increase the proportion of patients operated on by a brain and CNS surgeon with a specialist interest in tumours. This will require a reorganisation of surgical teams which is likely to be challenging for services managing smaller populations. Also, the NCAG is considering whether to recommend minimum numbers of patients for each sub-specialist multidisciplinary team for very rare tumours (pituitary, spinal cord and skull base tumours where most of the centres host specialist multidisciplinary teams for these cancer types).

London cancer networks have identified gaps in core and extended specialist multidisciplinary team membership and resources for rehabilitation services for brain and CNS services. As with head and neck services, service
infrastructure needs to be improved to ensure high quality rehabilitation and aftercare services.

**Key messages**

Supportive care and rehabilitation for brain and CNS services are of key importance and are not integrated with these services across London.

The IOG requires minimum volumes for brain and CNS tumours and the range in populations served by centres suggests fewer services could manage increased volumes per multidisciplinary team with more effective use of the specialist resource.

The national clinical advisory group for brain and CNS tumours is further considering minimum volumes for each subspecialist multidisciplinary team for very rare tumours in this category. This is expected to require further concentration of specialist multidisciplinary teams in London.

### 5.7 Gynaecological cancers

Gynaecological cancers include ovarian germ cell tumours, endometrial (cancer of the uterus), cervical, vulval and vaginal tumours.

The gynaecological cancers IOG\(^{180}\) stipulates that specialist multidisciplinary teams should serve populations exceeding one million. Diagnostic teams should be in a local hospital setting, and treatment in a specialist centre.

There are detailed requirements for endometrial, cervical, ovarian, vulval and vaginal cancers. These specify which treatments may be managed by designated local services and those that should be managed by the specialist multidisciplinary team, located in a cancer centre. Designated procedures must take place at these centres.

Figure 33 shows the London providers for gynaecological cancer surgery and the six designated specialist centres.

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\(^{180}\) NICE, *Improving Outcomes in Gynaecological Cancers: The manual*, 1999
Every network has a specialist multidisciplinary team. The range in populations served by centres suggests fewer services could manage increased volumes per multidisciplinary team with more effective use of the specialist resource.

There is variation across London in length of stay for gynaecological surgical operations and the provision of supportive services. Providers need to focus on reducing length of stay, where appropriate. The target length of stay is three to four days. Currently some hospitals are reporting inpatient bed days of up to 18.\textsuperscript{181}

All patients do not currently have access to supportive care (for example, laparoscopic ovarian transposition to maintain ovarian function in women having pelvic radiotherapy); and to reproductive medicine consultation, in vitro fertilisation (IVF), and embryo cryopreservation, where appropriate, before curative but fertility destroying treatment for cancer.

**Key messages**

The IOG requires minimum volumes for gynaecological tumours and the range in populations served by centres suggests fewer services could manage increased volumes per multidisciplinary team with more effective use of the specialist resource.

\textsuperscript{181} Source: HES 2007 microsite, NATCANSAT
There is variation across London in length of stay for gynaecological surgical operations and the provision of supportive services.

5.8 Sarcoma

Sarcomas are a rare and diverse group of cancers that arise from cells that make up the connective tissue structure, including bone, cartilage, muscle, blood vessels, nerves and fat. About 2,200 people a year in the UK will be diagnosed with a sarcoma but of them, fewer than 500 people per year are diagnosed with a bone sarcoma.

Soft tissue sarcomas can occur anywhere that connective tissue is present and the signs and symptoms vary greatly depending on the anatomic site, as do the treatment options and prognosis. Soft tissue sarcomas increase in frequency with age. Surgery is the most common form of treatment but this is changing with increasing use of chemotherapy for some tumour types.

The age-specific frequencies of primary bone sarcomas are bimodal; the first peak occurring during the second decade of life, associated with the growth spurt, and the second occurring in patients older than 60 years. They are more common in males than in females. Most people with primary bone cancer will need a combination of surgery, chemotherapy and radiotherapy as treatment.\(^{182}\)

The sarcoma IOG stipulates that soft tissue sarcoma specialist multidisciplinary teams should serve a population of two to three million and bone sarcoma specialist multidisciplinary teams should serve a population of seven million. A soft tissue sarcoma specialist multidisciplinary team should manage the care of at least 100 new patients per year. If a sarcoma specialist multidisciplinary team manages the care of patients with both bone and soft tissue sarcoma, it needs to manage the care of at least 50 new patients with bone sarcoma per year, in addition to the 100 new patients with soft tissue sarcoma per year.

There are two soft tissue sarcoma centres in London. One of them is a combined bone and soft tissue sarcoma centre split across two sites; it is one of the five national supra-regional bone tumour treatment centres. There is general consensus among London cancer networks that the number of providers in London is correct.

One of the key components of the sarcoma IOG is the creation of linkages between multidisciplinary teams in upper gastrointestinal, gynaecological, and head and neck so that sarcomas occurring in these anatomical sites can have input from a sarcoma multidisciplinary team. Currently some patients may not be receiving the optimal treatment and not then benefiting from treatment developments, which are available via the two London sarcoma centres. These centres have greater knowledge of the treatment options; provide greater access to clinical trials, and are able to offer holistic support to sarcoma patients.

\(^{182}\) NICE, *Improving Outcomes for People with Sarcoma*, 2006
Key message

Services for sarcoma are currently configured appropriately in London. Improved communication between sarcoma multidisciplinary teams in London and multidisciplinary teams dealing with sarcomas occurring in other sites including upper gastrointestinal, gynaecological, and head and neck, would ensure sarcomas diagnosed at these sites are referred and managed appropriately.

5.9 Specialist treatments

5.9.1 Haematopoietic progenitor cell transplantation (HPCT)

Haematopoietic progenitor cell transplantation is the transplantation of blood stem cells derived from the bone marrow or blood.

The Joint Accreditation Committee of International Society for Cellular Therapy and European Group (JACIE) accreditation standards for bone marrow transplantation requires transplant centres to perform a minimum of at least 10 autografts and/or at least 10 allografts a year, or to be a linked satellite centre of an accredited centre. Only accredited centres are allowed to harvest stem cells and perform transplants.

HPCT requires a high level of expertise, including specialist medical and nursing expertise, and a range of specialist clinical support facilities, including specialist gastroenterological, renal and pulmonary units; cardiology; dermatology; infectious diseases; and access to intensive care and photopheresis. Essential specialised laboratory facilities include cytogenetics, molecular studies, specialist virology and tissue typing.

In 2007/08 there were 10 adult transplant units in London. This has now reduced to nine, five of which are JACIE accredited, and one of which is collocated with a paediatric transplant unit.

Provider volumes should be reviewed given the high level of expertise and range of facilities required.

Growth in activity is projected for 2009/10\(^{183}\) resulting from NICE IOG implementation, including improved screening and the introduction of multidisciplinary haematology teams to improve equality of access. Managing demand is particularly difficult for this service where transplant may be the only option available to the patient. The London Specialised Commissioning Group stipulates that multidisciplinary teams have a key role in ensuring only appropriate patients are referred to the transplant programme.

Key message

The high level of expertise and range of facilities required for haematopoietic

\(^{183}\) The London Specialised Commissioning Group, Adult BMT consortium 2009/10 operating plan, January 2009
progenitor cell transplantation (HPCT) suggests fewer services could manage increased volumes per multidisciplinary team with more effective use of the specialist resource.

5.9.2 Molecular diagnostics

In future, a significant element of the management of cancer patients will be determined by techniques and information obtained through genomic and proteomic profiling technologies, which will be combined with sophisticated imaging modalities. These will supplement traditional histopathological studies. Identifying different molecular markers will predict patient resistance to, and benefit for specific targeted therapy. Targeting therapy according to a tumour’s molecular profile leads to better outcomes. Using targeted therapy, fewer patients are exposed to toxicities unnecessarily because the choice of drug can be individualised. It is also cost-effective because only those patients likely to respond receive the therapy.

Currently, access to specialist diagnostic services varies across the capital. Haematopathology diagnostics, which have been used as a pilot service to develop such integrated reporting, illustrate the patchy nature of provision.
5.9.3 Specialist imaging

Developments in imaging are enabling teams to determine, prior to surgery, whether surgery is the best option for the patient. For example, Positron Emission Tomography-Computerised Tomography (PET-CT) scanning enables accurate locating of the tumour(s) and tumour staging. Specialist imaging technologies can potentially reveal unsuspected metastatic spread of disease and avoid an unhelpful operation with non-surgical treatments being carried out instead.

The integration of imaging technologies, such as PET-CT scanning, ultrasound and MRI, is an important element in diagnosis, staging and response assessment because frequently more than one modality is required to define abnormalities. It can also be an early predictor of tumour response to therapy. This benefits patients as they need not stay on toxic treatment for a prolonged period of time waiting for measurable response to occur. It is also cost-effective for the same reason.

5.9.4 Specialist radiotherapy

Stereotactic radiotherapy describes the delivery of radiotherapy where the patient is immobilised in a rigid frame. Stereotactic treatment can be delivered by gammaknife or a linac based system. This allows higher, and potentially more effective, doses to be delivered accurately to small targets. Stereotactic radiotherapy may permit standard doses to be delivered with fewer side effects.

Stereotactic radiotherapy is commissioned mainly by specialised commissioning groups as a specialised service. There is one NHS provider in Sheffield and two private providers in London. Its growing use in the treatment of cerebral metastases is leading to pressure on specialised commissioning groups to invest in increasing provision nationally. A review of evidence is required and a proposal has been submitted to the UK Health Technology Assessment Programme for consideration.

Cyberknife radiotherapy is a new technology that can also deliver forms of stereotactic treatment. Cyberknife uses the same type of radiation that is used in conventional radiotherapy, but unlike conventional radiotherapy, it can safely place a huge dose of radiation on the target without over-irradiating the surrounding normal body tissues. Such a high dose of radiation delivered to the tumour can destroy it as effectively as removal by a surgical operation.

Cancers and tumours in the head, brain, spine, lung, liver, pancreas, prostate and sarcomas may all respond well to this new technique but more research on the safety and efficacy of this treatment is required.\(^{184}\) The cyberknife can also treat metastases, where the primary cancer has spread to other parts of the body.\(^{185}\)

Currently, cyberknife radiotherapy is only available in two private radiotherapy departments in London.


\(^{185}\) London Prostate Cancer Centre, Cyberknife, accessed October 2009 <http://www.prostatecancertreatment.co.uk/treatment-options/cyberknife/>
Proton beam therapy is a form of radiotherapy that has the ability to focus precisely on the tumour even if it is close to critical structures.

The UK has no modern, high energy proton treatment facility for patients other than for tumours of the eye. This contrasts with most European countries, where such centres are either available or being commissioned and planned. A national programme to procure a very small number of services for England will be coordinated through the National Commissioning Group. Various centres in London treat tumours that would benefit from the advantages of proton beam therapy.

Total Body Irradiation is used to prepare patients to receive bone marrow transplants (HPCT).

Intensity-modulated radiation therapy is an advanced mode of high-precision radiotherapy that utilises computer-controlled linear accelerators to deliver precise radiation doses to conform more precisely to the three-dimensional shape of a tumour. Intensity-modulated radiation therapy is being used most extensively to treat cancers of the prostate, head and neck and CNS.

**Key message**

The provision and justification of specialist treatments in London should be considered, so that these technologies are concentrated to justify the cost, and with sufficient trained staff to utilise them.

**5.10 Section summary**

This section made the case for change for further centralisation for oesophago-gastric, pancreatic, head and neck and endocrine, gynaecological, and brain and CNS services. The case for the provision and concentration of HPCT transplant services, and specialist treatments is also outlined. For rare urological and sarcoma services, the case is made for retaining current service configuration.
6. Conclusion

The key issues impacting on London’s cancer services are well known to healthcare professionals working in this area and have been highlighted in this case for change. More work is now needed to steer these services into an appropriate pan-London model of care.

Integrated commissioning of all cancer services needs to be at the centre of change, given that most services are highly dependent on each other. The importance of research-focused multidisciplinary teams supporting these services has been highlighted in this document. It therefore needs to be emphasised that planning each service in isolation does not take into account interdependencies and often leads to unsustainable service models.

Interdependencies and patient pathway flows between care settings need to be recognised in developing new delivery models, to ensure relationships are strengthened and not fractured. An integrated approach is particularly important to support the more disadvantaged groups in London’s diverse population and to tackle the inequalities that exist in health and in access to health services, including unscheduled care.
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**Glossary**

**A Framework for Action:** A report written by Professor the Lord Ara Darzi and published by NHS London in July 2007 outlining a strategy to meet London’s health needs over the next five to 10 years.

**Academic Health Science Centres (AHSCs):** A partnership between one or more universities and healthcare providers focusing on research, clinical services, education and training.

**Allograft:** The transplantation of cells, tissues, or organs, sourced from a genetically non-identical member of the same species as the recipient.

**Aplastic anaemia:** A condition where bone marrow does not produce sufficient new cells to replenish blood cells.

**Autograft:** The transplantation of organs, tissues or even proteins from one part of the body to another in the same individual.

**Bio-bank:** A place that collects, stores, processes and distributes biological materials and the data associated with those materials.

**Bio-informatics:** The application of information technology to the field of molecular biology.

**Biomarker:** A substance used as an indicator of a biological state and is a characteristic used in many scientific fields as an indicator of normal biological responses to a therapeutic intervention.

**BME:** Black and minority ethnic.

**Brachytherapy:** A form of radiotherapy where a radioactive source is placed inside or next to the area requiring treatment.

**Breast-conserving therapy (BCT):** The treatment of a breast tumour by biopsy, lumpectomy, partial mastectomy, re-excision, quadrantectomy, or wedge resection.

**Cancer Awareness Measure:** A tool designed to measure symptom awareness of cancer among the general public.

**Cancer Commissioning Toolkit:** An online library of key cancer information and data developed to support PCTs to develop their strategies for implementing the Cancer Reform Strategy.

**Cancer Reform Strategy:** A strategy published in 2007, building on progress made since the publication of the NHS Cancer Plan in 2000, setting out a programme of action across 10 areas to be achieved by 2012.

**Clinical nurse specialist:** A nurse specialist in clinical practice who has undertaken formal recognised post-registration education and acts as a specialist resource to improve patient management.
**Colorectal:** Pertaining to the colon and rectum.

**Co-morbidity:** The effect of all other diseases an individual patient might have other than the primary disease of interest.

**Computerised tomography (CT):** A medical imaging method employing tomography undertaken in sections through the use of wave of energy, created by computer processing.

**Cryopreservation:** A process where cells or whole tissues are preserved by cooling to low sub-zero temperatures.

**Cyberknife radiotherapy:** A method of delivering radiotherapy, with the intention of targeting treatment more accurately than standard radiotherapy.

**Cytogenetics:** A branch of genetics concerned with the study of the structure and function of the cell, especially the chromosomes.

**Endocrine:** Relating to glands that involve the release of hormones.

**Enhanced Recovery after Surgery (ERAS):** A method of patient management (pre/intra/post-operative) to aid recovery and reduce length of stay.

**Epidemiology:** The study of factors affecting the health and illness of populations.

**European Group for Blood and Marrow Transplantation:** A non-profit organisation based in The Netherlands, providing a forum for scientists and physicians involved in clinical bone marrow transplantation to share their experience and develop cooperative studies.

**European Working Time Directive:** A collection of regulations concerning hours of work, designed to protect the health and safety of workers.

**Fractionation:** Administering of radiotherapy in regular doses at regular intervals over a period of time.

**Genomic:** Pertaining to genes and the non-coding sequences of DNA.

**Gynaecological:** Pertaining to the female reproductive system.

**Haematological:** Pertaining to the study of blood, blood-forming organs, and blood diseases.

**Haemoglobinopathies:** Inherited single-gene disorders.

**Hepatic:** Of, or pertaining to the liver.

**Hepatocellular carcinoma (HCC):** A primary malignancy of the liver.

**Hepato-Pancreato-Biliary (HPB):** A medical term used in conjunction with conditions and procedures related to the liver, pancreas and biliary tract.
**Haematopoietic progenitor cell transplantation (HPCT):** The transplantation of blood stem cells derived from the bone marrow or blood.

**Human papilloma virus (HPV):** A papillomavirus that infects the epidermis and mucous membranes of humans, which can lead to cancers of the cervix, vulva, vagina, and anus in women and cancers of the anus and penis in men.

**Image-guided radiation therapy:** The process of frequent two and three-dimensional imaging, during a course of radiation treatment, used to direct radiation therapy utilising the imaging coordinates of the actual radiation treatment plan.

**Improving Outcomes Guidance (IOG):** Service guidance produced by the National Institute for Health and Clinical Excellence on outcomes for patients.

**Intensity-modulated radiation therapy:** The medical use of ionizing radiation as part of cancer treatment to control malignant cells.

**International Society for Cellular Therapy (ISCT):** The global forum and resource for developing and supporting innovative cellular therapies.

**Joint Accreditation Committee of ISCT & EBMT (JACIE):** A non-profit body established in 1998 for the purposes of assessment and accreditation in the field of bone marrow transplantation.

**Joint Council for Clinical Oncology (Joint Collegiate Council for Oncology JCCO):** A jointly established council between the Royal College of Physicians and the Royal College of Radiologists to develop policies related to the development of cancer care and research.

**Keyworker:** A person who, with patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity; ensuring the patient knows who to access for information and advice.

**Laparoscopic surgery:** A modern surgical technique in which operations in the abdomen are performed through small incisions, also called minimally invasive surgery, bandaid surgery and keyhole surgery.

**London Cancer New Drugs Group:** A sub-committee of the London Cancer Networks Steering Group who has delegated responsibility to develop recommendations for the managed entry of new treatments in cancer across London.

**Linear particle accelerator (Linac):** Used to treat all parts/organs of the body to deliver a uniform dose of high energy X-ray to the region of the patient’s tumour.

**London Cancer Network Board:** A pan-London board comprising of representatives from the five London cancer networks.

**London Specialised Commissioning Group:** A joint committee of London PCTs working in partnership with neighbouring specialised commissioning groups, NHS London, patient and public engagement groups and NHS trusts that commissions specialised services collaboratively using a variety of contracting and financial risk-
sharing arrangements, run by consortia.

**Maxillofacial**: Pertaining to the jaws and face.

**Multidisciplinary team**: A group of expert doctors, nurses and other healthcare professionals with a special interest in the diagnosis, treatment and management of people with cancer.

**Mediastinum**: A non-delineated group of structures in the thorax, surrounded by loose connective tissue.

**Metastasise**: The spreading of a disease from one organ or part to another non-adjacent organ or part.

**Magnetic resonance imaging (MRI)**: A medical imaging technique most commonly used in radiology to visualise the internal structure and function of the body.

**National Audit Office**: The body that audits central government accounts and reports to Parliament on the value for money achieved by government projects and programmes.

**National Awareness and Early Detection Initiative (NAEDI)**: An initiative with the role of coordinating and supporting activities that promote the early diagnosis and treatment of cancer.

**National Cancer Action Team (NCAT)**: A team that reports to the national cancer director. Its role is to support the NHS and facilitate the implementation of the *Cancer Reform Strategy*, working alongside the cancer policy team in the Department of Health and with NHS cancer networks.

**National Cancer Peer Review Programme**: A national quality assurance programme for NHS cancer services.

**National Chemotherapy Advisory Group (NCAG)**: A group commissioned by the Department of Health to recommend how chemotherapy services should be developed.

**National Collaborating Centre for Primary Care (NCCPC)**: A partnership of primary care professional associations formed as a collaborating centre to develop guidelines under contract to the National Institute for Health and Clinical Excellence.

**National Confidential Enquiry into Patient Outcome and Death (NCEPOD)**: Assists in maintaining and improving standards of medical and surgical care by reviewing the management of patients and undertaking confidential surveys and research.

**National Institute for Health and Clinical Excellence (NICE)**: An independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

**National Radiotherapy Advisory Group (NRAG)**: A group set up in 2004 to advise Ministers on how to improve radiotherapy services in England.
**Nephrectomy:** The surgical removal of a kidney.

**Oesophago-gastric:** Pertaining to the oesophagus and stomach.

**Orchidectomy:** Surgical excision of a testis or of both testes.

**Palliative:** Any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

**Peri-operative:** The period around the time of a surgical operation.

**Photopheresis:** A form of aphaeresis in which blood is treated with photoactivable drugs that are then activated with ultraviolet light.

**Positron Emission Tomography-Computerised Tomography (PET-CT) Scanning:** A nuclear medicine imaging technique, which produces a three-dimensional image or picture of functional processes in the body.

**Proteomic:** Pertaining to the structure and function of proteins.

**Proton beam therapy (PBT):** A type of particle therapy that uses a beam of protons to irradiate diseased tissue, most often in the treatment of cancer.

**Radiotherapy:** The medical use of ionising radiation as part of cancer treatment to control malignant cells.

**Sarcoma:** A malignant tumour arising in tissue of mesodermal origin (as connective tissue, bone, cartilage, or striated muscle) that spreads by extension into neighbouring tissue or by way of the bloodstream.

**Seminoma:** A type of testicular cancer.

**Sigmoidoscopy:** The minimally invasive medical examination of the large intestine from the rectum through the last part of the colon.

**Significant Event Audit:** The analysis and shared learning of a significant positive or negative patient outcome.

**Spearhead group:** The highest fifth of areas with the worst health and deprivation indicators in England.

**Stereotactic radiosurgery:** A medical procedure that allows non-invasive treatment of benign and malignant tumours.

**Systemic anti-cancer therapy:** Used to kill or slow the growth of cancer cells (as palliative treatment), or post-surgery for cancer cells still remaining. Systemic anti-cancer therapy comprises chemotherapy, endocrine therapy and hormonal therapy.

**Thoracic:** Pertaining to the region of the body formed by the sternum, the thoracic vertebrae and the ribs extending from the neck to the diaphragm not including the upper limbs.
**Total body irradiation:** A form of radiotherapy used primarily as part of the preparative regimen for haematopoietic progenitor cell transplantation (or bone marrow) transplantation.

**Trans-anal endoscopic microsurgery (TEMS):** A specially designed technique that allows surgery to be performed in the rectum using a special instrument called an endoscope.

**Upper aerodigestive tract (UAT):** Referring to areas of the head and neck including lip, mouth, oral cavity, salivary glands, sinuses, pharynx and larynx.

**Upper gastrointestinal:** Refers to oesophagus, stomach and duodenum.

**Urological:** Referring to the urinary tracts of males and females and the reproductive system of males.

**Virology:** The study of viruses and virus-like agents.
Appendices

Appendix 1: Expenditure on cancer services in London

Cancer care is recorded across a wide range of Healthcare Resource Group (HRG) categories and includes a high proportion of locally priced services, in particular the cost of drugs used in chemotherapy. For this reason a number of estimations are required in assessing the totality of cost, the methodology used is laid out in detail in the final section of this appendix.

Summary

Cancer care takes place in primary, secondary and tertiary care settings. Across England it is estimated that more than £3.6bn is spent on cancer care in both secondary and tertiary care (excluding screening costs). In London it is estimated that cancer care in hospitals costs London PCTs in excess of £0.5bn. This is broken down as follows.

| Total cancer care commissioned by London PCTs with London trusts (estimated to be £546m) |
| Inpatients £241m | Nationally contracted £5m |
| Radiotherapy £24m |
| Outpatients £64m |
| Day patients £123m |
| Chemotherapy drugs £89m |

Import and export of treatment from London

London’s hospitals provide services to not just London residents, but to those from further afield. The flows of cancer inpatients into London account for more than 20% of provider activity while the outflows from London PCTs to non-London providers are three per cent of PCT’s expenditure on inpatient cancer care.

This is a higher proportion than for many acute services and reflects the specialist nature of some of the services provided. In deciding future service provision these flows will need to be taken into account.

An analysis of inpatient flows is as follows:
Cancer income by London provider

Imported work is particularly important to some London trusts as can be seen below (figures throughout this appendix exclude private patient’s income, which is a particularly important source of income at the Royal Marsden NHS Foundation Trust, totalling over £40m).

There is an approximate average of six per cent for trusts, but specialist trusts derive 12-15% of operating income from cancer. For the Royal Marsden NHS Foundation Trust, the figure is 60% excluding private patients.
Common and rare cancers

Analysing the cost to PCTs of inpatient cancer treatments (excluding contract excluded drugs) by the categories proposed by the project, gives an indication of the relative resource consumption of each of the categories.
An analysis of attenders, day patients and inpatient spell numbers and cost, across the project categories is as follows:

Note – this analysis covers only day and inpatient costs.

### Spending by London PCTs

The level of PCT expenditure on cancer will depend on a number of factors. These include population size, incidence of cancer, how early cancers are detected and the level of private healthcare. After standardising for population size, the following chart indicates that there is a visible difference in spend per head of population on cancer services between PCTs.
Chemotherapy

The cost of chemotherapy to London PCTs is estimated to be over £80m. This equates to more than £2.5m per PCT.

Radiotherapy

The cost of radiotherapy to London PCTs is estimated to be £30m (taken from PCT budgets for 2009/10). This equates to almost £1.0m per PCT.

Early diagnosis

The costs of early diagnosis are embedded in primary care and secondary care settings. They include general practice costs, screening costs (radiology and pathology). Breast screening costs are the only costs that are easily visible and are estimated to be £15m for London (£0.5m per PCT).

Sources of information

Cancer care is recorded across a wide range of HRG categories and includes a high proportion of locally priced services. Consequently there is a degree of estimation in the costs shown.
The main area of uncertainty in the figures is related to Payment by Results (PbR) exclusions:

- Drugs where those related to cancer are not consistently identified by trusts, or in some cases, are not recorded.
- Locally priced procedures which are not included in HES.

**Inpatients** – are taken directly from 2007/08 HES data and priced using 2007/08 national or indicative prices. Totals derived are inflated to 2009/10 prices. Costs are not adjusted for short stay or paediatric supplements which will occur in a small number of instances.

- As cancer is not easily identifiable by HRG, for this exercise cancer is defined where one of the first three diagnosis codes includes a C or D prefix.
- Day patients and day attendees are defined as those with a spell duration of zero.
- In addition there are locally priced procedures such as BMT which are not directly identifiable in HES data. An estimate of BMT is included, based on procedure numbers and indicative prices.
- PCT and all London charts exclude trust imports from non London PCTs. Information by trust includes imports to give a full picture.

**Outpatients** – data is taken from HES, as with inpatients. Only medical and clinical oncology are directly identified in outpatient data; appointments following surgery, for example, are coded to the appropriate treatment specialty. For this reason an estimate of the missed cost is included and based on the number of inpatient procedures recorded.

**Drugs** – chemotherapy drug costs have been taken from the 2009/10 budgets which trusts have included in secondary user service. Some trusts record the cost of chemotherapy drugs specifically, while others include the costs with other PbR exclusions. In addition, a number of excluded drugs, which are not classified as chemotherapy, are used in cancer treatment.

This analysis includes the full cost of specific chemotherapy drugs and includes an estimate based on numbers of treatments where chemotherapy drugs are not specifically identified.

No estimate of the use of other excluded drugs is included.

**Nationally contracted** – is derived from a summary of nationally contracted procedures.
## Appendix 2: List of full provider names

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Name of NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>BCFH</td>
<td>Barnet and Chase Farm Hospitals NHS Trust</td>
</tr>
<tr>
<td>BH</td>
<td>Bromley Hospitals NHS Trust</td>
</tr>
<tr>
<td>BHR</td>
<td>Barking, Havering and Redbridge Hospitals NHS Trust</td>
</tr>
<tr>
<td>BLH</td>
<td>Barts and The London NHS Trust</td>
</tr>
<tr>
<td>C&amp;WH</td>
<td>Chelsea and Westminster Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>EH</td>
<td>Ealing Hospital NHS Trust</td>
</tr>
<tr>
<td>ESHUH</td>
<td>Epsom and St Helier University Hospitals NHS Trust</td>
</tr>
<tr>
<td>GOSH</td>
<td>Great Ormond Street Hospital for Children NHS Trust</td>
</tr>
<tr>
<td>GST</td>
<td>Guy’s and St Thomas’ NHS Foundation Trust</td>
</tr>
<tr>
<td>HH</td>
<td>The Hillingdon Hospital NHS Trust</td>
</tr>
<tr>
<td>HUH</td>
<td>Homerton University Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>ICH</td>
<td>Imperial College Healthcare NHS Trust</td>
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<tr>
<td>KCH</td>
<td>King’s College Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>KH</td>
<td>Kingston Hospital NHS Trust</td>
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<tr>
<td>LH</td>
<td>The Lewisham Hospital NHS Trust</td>
</tr>
<tr>
<td>MH</td>
<td>Mayday Healthcare NHS Trust</td>
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<tr>
<td>NMUH</td>
<td>North Middlesex University Hospital NHS Trust</td>
</tr>
<tr>
<td>NUH</td>
<td>Newham University Hospital NHS Trust</td>
</tr>
<tr>
<td>NWLH</td>
<td>North West London Hospitals NHS Trust</td>
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<tr>
<td>QEH</td>
<td>Queen Elizabeth Hospital NHS Trust</td>
</tr>
<tr>
<td>QMS</td>
<td>Queen Marys Sidcup NHS Trust</td>
</tr>
<tr>
<td>RBH</td>
<td>Royal Brompton &amp; Harefield NHS Foundation Trust</td>
</tr>
<tr>
<td>RFH</td>
<td>Royal Free Hampstead NHS Trust</td>
</tr>
<tr>
<td>RMH</td>
<td>The Royal Marsden NHS Foundation Trust</td>
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<tr>
<td>RNOH</td>
<td>Royal National Orthopaedic Hospital NHS Trust</td>
</tr>
<tr>
<td>SGH</td>
<td>St George’s Healthcare NHS Trust</td>
</tr>
<tr>
<td>SLH</td>
<td>South London Healthcare NHS Trust</td>
</tr>
<tr>
<td>UCLH</td>
<td>University College London Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>WCUH</td>
<td>Whipps Cross University Hospital NHS Trust</td>
</tr>
<tr>
<td>Code</td>
<td>Hospital Name</td>
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<tr>
<td>------</td>
<td>---------------------------------------------------</td>
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<tr>
<td>WH</td>
<td>The Whittington Hospital NHS Trust</td>
</tr>
<tr>
<td>WMUH</td>
<td>West Middlesex University Hospital NHS Trust</td>
</tr>
</tbody>
</table>
Appendix 3: A note on the procedure volume charts used in the case for change

The majority of procedure volume charts in this document show a single figure for each provider. These charts show the number of defined procedures carried out on patients with a primary diagnosis of a tumour at the site operated upon. For example, prostatectomies carried out when the primary diagnosis is a prostate tumour.

For some tumour types, a significant proportion of surgical procedures undertaken by the same specialist multidisciplinary team are on patients with either:

- a primary diagnosis of a tumour at a site other than the site operated upon (for example, pancreatectomies carried out when the primary diagnosis is a stomach tumour); or
- other disease.

In such cases it has been necessary to add these additional figures in the charts to illustrate maintenance of clinical expertise.

These charts appear as tiered bar charts showing:

- The number of defined procedures carried out on patients with a primary diagnosis of a tumour at the site operated upon.
- The number of defined procedures carried out on patients with a primary diagnosis of a tumour at a site other than the site operated upon.
- The number of defined procedures carried out on patient where the primary diagnosis is not a tumour.