

commissioning cancer services

Welcome to Commissioning Cancer Services, supporting world-class commissioning of cancer services

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Second edition





INFORMATION READER BOX

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Commissioning Cancer Services in the NHS – Welcome

This is a transitional update to the Cancer Commissioning Guidance, first published in January 2009, to support the commissioning of cancer services across the NHS.

This document should be read alongside the web-based Cancer Commissioning Toolkit (CCT), an online library of key cancer information and data which can be easily accessed by commissioners for use in the preparation of their commissioning plans.

Over two years on, many changes have taken place and many more are now in the pipeline as the Government implements its plans for the NHS. Improving Outcomes: A Strategy for Cancer (IOSC) was published by the Department of Health (DH) in January 2011. It recognised that we are now in a period of transition as a number of structural changes designed to underpin the Government's reforms of health and social care are put in place. IOSC made the commitment to further develop both the CCT and the Commissioning Cancer Services guidance to focus on what works best in supporting pathfinder commissioners and the proposed NHS Commissioning Board, and to produce a commissioning support pack.

However, recognising that services will continue to be commissioned during transition, this update is intended to reflect those changes that have taken place in the last two years and indicate where significant changes are to come in order to continue to support commissioners through transition. References to 'commissioners' should be read as relating to primary care trust (PCT) commissioners now and, subject to Parliamentary approval of the Health and Social Care Bill 2011, commissioners/NHS Commissioning Board in the longer term and as commissioning responsibilities transfer.

This best practice document sets out key issues and questions that commissioners and cancer network teams will wish to take into consideration when assessing local health needs and when reviewing services, developing their contract service specifications and monitoring performance.

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1. Introduction

Improving Outcomes: A Strategy for Cancer (IOSC) was published in January 2011, setting out the ways in which the Government will meet its aims of delivering healthcare outcomes as good as anywhere in the world.

Commissioning is key to delivering improvements in outcomes, and IOSC sets out how the quality of the commissioning of cancer services will be improved, ensuring that decisions are focused on the needs of patients. Through stronger commissioning we will improve outcomes for all cancer patients and achieve the aim of improving cancer survival rates. We aim to save an additional 5,000 lives every year by 2014/15 and narrow the inequalities gap at the same time.

The expectation that IOSC will be implemented was also set out in *The Operating Framework for the NHS in England 2011/12* (DH, 2010). This highlights that commissioners and providers will:

- need to ensure that services are being planned, commissioned and delivered based on the current suite of cancer waiting times standards
- want to consider four priority areas for diagnostics for improving earlier diagnosis and ensuring smooth transition: chest X-ray, non-obstetric ultrasound, flexi sigmoidoscopy and MRI brain
- improve outcomes from radiotherapy treatments for cancer patients

- work with their networks to implement outstanding National Institute for Health and Clinical Excellence (NICE) Improving Outcomes Guidance documents
- provide data to assess progress on improving survival rates.

The Operating Framework also sets out key actions that will need to be taken to ensure that screening services improve clinical outcomes. It can be found at: www.dh.gov.uk/en/Managingyourorganisation/ Financeandplanning/Planningframework/index.htm

This document sets out best practice guidance and has been further developed to support NHS commissioners in the successful implementation of IOSC. It is in two parts:

- The first section highlights the organisational competencies that those involved in cancer commissioning will want to focus on.
- The second section sets out key issues and key questions that commissioners/network teams will want to take into consideration when assessing health needs, reviewing services, developing their contract service specifications and monitoring performance. A variety of existing datasets and clinical audits have been signposted throughout, some of which are mandatory for completion but others of which may also prove useful in benchmarking local performance nationally.

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The first section will be developed further as the transition of the NHS progress, and will describe the new structures for commissioning cancer services, their roles and responsibilities.

The web-based CCT sits alongside this document. The CCT provides an easily accessible 'one-stop' source of cancer information bringing together national published information on cancer held in different places (cancer registry, cancer screening services, Hospital Episode Statistics (HES), cancer peer review, programme budgeting, bespoke national analyses, etc). The CCT brings this information together into a single, webbased product including Commissioner and Practice Profiles. Metrics have been selected and benchmarked to answer key commissioning questions.

Throughout the Outcomes Framework and the CCT there are other links to best practice policy and documents as well as to the NHS Improvement website. This is to ensure that commissioners and network teams have ready access to examples of service innovation. We will continue to build this library, and welcome suggestions.

The National Cancer Action Team (NCAT) and the National Cancer Intelligence Network (NCIN) will support commissioners, network teams and other stakeholders to use the CCT, and will continue to work with them on further refinements and developments through transition. It is hoped that by making more use of the information that is available, data accuracy will improve. Significant support in developing the information has come from the National Cancer Statistical Analysis Team, as well as the cancer registries and cancer screening programmes.

During transition, cancer networks will support pathfinder commissioners to improve the commissioning of cancer services.

Until the new NHS structures are in place, the implementation of the first stages of IOSC will be supported by the bodies that make up the National Cancer Programme: NCAT, NHS Improvement and the NCIN.

1.1 Extract from *Improving Outcomes: A Strategy for Cancer* (section 8) [N.B. Predates listening exercise]

Commissioning of cancer services

8.3 Commissioning for cancer is particularly complex. There are many different types of cancer, each requiring different interventions with a different care pathway. The other important element of complexity is the co-ordination of services across the treatment and care pathway for the patient. For each cancer this involves health and social care teams in general practice, in the community, in acute general hospitals and in specialist centres.

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- 8.4 Where the diagnosis and treatment of cancer are rare they require specialised commissioning, which are not appropriate for commissioners. The areas of cancer commissioning which are currently covered by national or regional specialised commissioning will continue to be subject to similar arrangements, through the NHS Commissioning Board.
- 8.5 A significant amount of cancer care is best commissioned for populations covering 1¹/₂–2 million. This includes specialist surgical services for upper gastrointestinal, urological, gynaecological, head and neck cancers and chemotherapy and radiotherapy. Where population size requirements mean that a single commissioner is too small to commission a particular service, then commissioners will wish to work collaboratively. Commissioners will be able to decide whether they wish to identify a lead consortium for commissioning more specialised cancer services (outside of NHS Commissioning Board commissioning) or to do so through commissioning support organisations. Commissioners will need support for commissioning, including for cancer services. Much is already available, but more will need to be provided and it will be for commissioners to source the support they deem is appropriate.
- 8.6 The Government's response to the NHS White Paper consultation, *Liberating the NHS: Legislative framework and next steps* (DH, 2010), set out detail about the proposed health and wellbeing boards in every upper-tier local authority, which will provide a mechanism for bringing together local NHS, public health and social care commissioners. This could provide a forum for the development of cross-cutting commissioning approaches to improve cancer services. Health and wellbeing boards will include elected representatives, local HealthWatch and key local commissioners for health and social care, including Directors of Public Health, adult social care and children's services.
- 8.7 The health and wellbeing boards will provide more effective engagement between local government and NHS commissioners. There will be a statutory obligation for the local authority and NHS commissioners to participate as members of the board and act in partnership. This will ensure that the services commissioned can better reflect local need and priorities.
- 8.8 To ensure joined-up commissioning at a local level, local authorities and commissioners will each have an equal and explicit obligation to prepare the Joint Strategic Needs Assessment (JSNA),

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and to do so through the health and wellbeing board. To build on the JSNA, and to ensure that collaboration is the norm, all health and wellbeing boards should have to develop a high level 'joint health and wellbeing strategy' that spans the NHS, social care, public health and could potentially consider wider health determinants such as housing or education.

- 8.9 The joint health and wellbeing strategy should provide the overarching framework within which commissioning plans for the NHS, social care, public health and other services the health and wellbeing board agrees are relevant are developed. At present JSNA obligations extend only to its production, not its application. To address this, the Health and Social Care Bill 2011 places a duty on commissioners to have regard to the JSNA and the joint health and wellbeing strategy when exercising their functions.
- 8.10 As some cancers are more common than others, NICE has defined appropriate population and activity thresholds for different cancer services in a series of evidence-based cancer Improving Outcomes Guidance documents (IOGs). In order to ensure quality care for patients, these IOGs will continue to be a feature of all commissioned services.

- 8.11 The library of Quality Standards being developed by NICE will be an important resource for commissioners in identifying issues to prioritise and will enable scrutiny of the extent to which they are commissioning high quality care. It is envisaged that the Commissioning Outcomes Framework, which will be used to incentivise high quality commissioning, will be closely aligned with the NICE Quality Standards. And for commissioners, the Commissioning for Quality and Innovation (CQUIN) payment framework will be important for ensuring the implementation of NICE Quality Standards by providers.
- 8.12 In developing a comprehensive suite of Quality Standards, NICE has made good early progress on key topics such as patient experience, end of life care and breast cancer. Further Quality Standards for colorectal, lung, ovarian and prostate cancer have been prioritised as part of the next tranche of the programme. These will be developed in 2011, and NICE will use them to support the production of more detailed commissioning best practice, to which commissioners must have regard when contracting for services. NICE have also been asked to assess the suitability of developing a Quality Standard on chemotherapy. The need for further Quality Standards to support the development of cancer services is also being

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Print this page Print this section considered as part of arrangements for defining the full suite of future standards. In the meantime, commissioners and providers can continue to draw on the clinical guidelines and Improving Outcomes Guidance that NICE has already developed for cancer services.

- 8.13 It is important that patients get access to new and emerging treatments and techniques as soon as possible during the transition. We will therefore publish advice to commissioners and providers on photodynamic therapy, stereotactic body radiotherapy and robotic surgery for prostate cancer in 2011.
- 8.14 The consultation for *Transparency in Outcomes: A framework for adult social care* (DH, 2010) sets out plans to expand NICE's remit to cover social care, which will allow for whole pathway Quality Standards which capture social care interventions to be developed from 2012.
- 8.15 The DH and the NCAT have previously provided commissioners with a range of guidance and support, such as the CCT and the Cancer Commissioning Guidance. We will also develop, in 2011, a cancer commissioning support pack to enable commissioners to access in one place the key information they will need to discharge

their functions effectively. This will include possible CQUIN goals, such as for improving patient experience.

8.16 As commissioners develop, it will be important that the DH and then the NHS Commissioning Board is able to respond to the developing needs of commissioners in relation to cancer.

Rewarding high quality care

- 8.17 In line with the comments in the recent National Audit Office (NAO) report, we need to ensure that we have better activity information and full clarity about costs for different services, and the right incentives to reward quality and efficiency. We are currently assessing what needs to be done in terms of responding effectively to the NAO recommendations.
- 8.18 In terms of having the right incentives to reward quality and efficiency, the DH has been working for some years to develop tariffs for chemotherapy and radiotherapy, and this work will be accelerated. In addition to taking forward the tariffs for chemotherapy and radiotherapy, during 2011/12 the DH will investigate the potential development of a range of tariffs to incentivise high quality, cost-effective services, including:

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- breast cancer screening
- bowel cancer screening (faecal occult blood test (FOBt), flexible sigmoidoscopy and colonoscopy elements)
- day case and overnight breast surgery, including one-stop axillary surgery
- new surgical techniques as they arise (so that there are incentives to develop appropriate training programmes quickly)
- avoidance of emergency admissions and readmissions
- the newest radiotherapy techniques, in particular Intensity Modulated Radiation Therapy (IMRT) (once the radiotherapy tariff has been introduced)
- good quality, personalised care pathways for cancer survivors – so that patients do not have to attend appointments unnecessarily, but all get the support and help they need to maximise their quality of life
- services for patients experiencing the late effects of cancer.

Supporting regulation

8.19 Equity and Excellence: Liberating the NHS (DH, 2010) made clear that the regulatory regime for providers of NHS services will be strengthened. From a cancer perspective, this will mean that the Care Quality Commission (CQC) will receive the following information feeds:

- screening quality assurance findings
- peer review findings (compliance scores and immediate risks)
- National Cancer Patient Experience Survey results
- case-mix adjusted clinical outcome data, as these become available.
- 8.20 The CQC will take a proportionate risk-based approach to regulation and inspection. Where the CQC has concerns about a provider or if, for example, peer review indicates there may be cause for concern, it will take a more pro-active approach. Failure to comply with the registration requirements is an offence and CQC has a wide range of independent enforcement powers. These range from the issue of a warning notice that requires improvement within a specified time, to prosecution and the power to cancel a provider's registration, removing its ability to provide regulated activities.
- 8.21 Through HealthWatch England, a part of CQC, there should be scope to tackle cancer inequality issues. In 2011 we will develop links between the National Cancer Equalities Initiative (NCEI) and HealthWatch.

End of extract from Improving Outcomes: A Strategy for Cancer (section 8).

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2. The challenge of cancer

2.1 Cancer incidence, mortality, survival and inequalities – undertaking a strategic needs assessment

2.1.1 Key issues

Over 250,000 people in England are diagnosed with cancer every year and around 130,000 die from the disease. Currently, about 1.8 million people are living with and beyond a cancer diagnosis. Even if we do not develop cancer ourselves, we are very likely to have family and friends who have had cancer. Surveys show that people fear cancer more than anything else.

Despite improvements in survival and mortality in recent decades, cancer outcomes in England remain poor when compared with the best outcomes in Europe. Although improvements have been made in the quality of cancer services, a significant gap remains in both survival and mortality rates. To put this in context, if England were to achieve cancer survival rates at the European average then 5,000 lives would be saved every year. If England were to achieve cancer survival rates at the European best then 10,000 lives would be saved every year. That is our challenge. There is a range of action needed to respond to this but, in particular, we need to:

- reduce the incidence of cancers that are preventable, by lifestyle changes
- improve access to screening for all groups and introduce new screening programmes where there is evidence that they will save lives and where they are recommended by the UK National Screening Committee
- achieve earlier diagnosis of cancer, to increase the scope for successful treatment – diagnosis of cancer at a later stage is generally agreed to be the single most important reason for the lower survival rates in England
- make sure that all patients have access to the best possible treatment.

And there are challenges in addition to the delivery of improved survival and mortality rates. In particular:

- many patients live with and beyond cancer for long periods of time, and we need to ensure that everything is done to allow them to live as healthy a life as possible, for as long as possible
- there are variations in patients' experience of care, and we need to make sure that feedback on patient experience informs the design and delivery of services so they reflect what is important to all patients
- inequalities in cancer mean that some groups in society have disproportionately poor outcomes.

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Improving Outcomes: A Strategy for Cancer (IOSC) has been informed by the evidence and analyses. These include:

- a new international benchmarking project, findings from which suggest that English survival rates continue to lag behind the best performing countries participating in the project and that, with the exception of breast cancer, we are not narrowing the 'survival gap' to move closer to the best performing countries¹
- an analysis of variations in drug usage across a number of different countries, which shows that the UK has a low ranking for the most recently licensed cancer drugs
- research into the way in which patients are first diagnosed with cancer, which shows that about a quarter of cancer patients are diagnosed via emergency routes and that the survival rates for those diagnosed via emergency routes are considerably lower than for other cancer patients
- a review of the quality of cancer registration, phase 1 of which concluded that deficiencies in cancer registration do not explain the differences in survival rates that have been observed

- results from clinical trials of screening for example, new research shows that a one-off procedure using flexi sigmoidoscopy to screen for bowel cancer could save 3,000 lives per year²
- measurement of service quality through peer review, which shows that performance is improving overall but is unacceptable in a small number of multidisciplinary teams
- a new Cancer Patient Experience Survey, which demonstrates which areas require more attention to improve patient experience.

2.1.2 Background

The first stage in cancer commissioning is to know your population; local cancer services; the views of patients; and the effectiveness of the local patient pathway(s). Local authorities and primary care trusts (PCTs) have a duty, under the Local Government and Public Involvement in Health Act 2007, to undertake a Joint Strategic Needs Assessment (JSNA) of the health and wellbeing needs of the local community – current changes will continue to ensure that the JSNA is used as the basis for developing a joint health and wellbeing strategy. *The NHS Outcomes Framework 2011/12* (DH 2010) and a future Public Health Outcomes Framework

1 Coleman MP, Forman D, Bryant H et al (2011) Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* 377(9660): 127–38.

2 www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_120076

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may help to inform priorities for these strategies, which will focus on local needs and priority outcomes.

Priorities identified in the JSNA should guide the development of the joint health and wellbeing strategies. The strategies will be implemented by commissioners represented on health and wellbeing boards, working together where appropriate. The strategies have the potential to act as an enabler for the funding of prevention, early detection and equality initiatives.

Cancer networks, through their commissioners, may wish to work to inform the JSNA, as well as be informed by its findings. For example, the JSNA is likely to help to identify communities or groups that are at risk of cancer on account of lifestyle choice, or that have problems accessing services due to transport problems or overall deprivation.

2.1.3 Needs assessment

Issues to take account of when assessing population needs are:

- demographic trends
- smoking rates and the impact of smoking cessation services and tobacco control policies
- other lifestyle risks, such as obesity, diet, lack of physical exercise, excess alcohol and exposure to sun/sunbeds
- ethnicity and other equality metrics

- access: age, deprivation, disability, ethnicity, gender reassignment, pregnancy and maternity, race, religion or belief, sex, and sexual orientation
- mortality, including the cancer contribution to all-age all-cause mortality, and the local position in improvements in mortality since the baseline in 1996/97. New information has been distributed by National Cancer Intelligence Network (NCIN) National Cancer Action Team (NCAT) (the cancer network quadrant analysis and the 'raindrop' analysis).

All cancer networks should have access to the data needed for the JSNAs. They should also have access to expertise to support commissioners, including local authorities, to interpret the information and make decisions about priorities to improve cancer outcomes.

2.1.4 Where to get more information on your population

The Association of Public Health Observatories (APHO) website (www.apho.org.uk) includes health profiles by local authorities, at both district/borough and county levels, which provide a consistent, concise, comparable and balanced overview of the population's health to inform local needs assessment, policy, planning, performance management, surveillance and practice. There is also a summary of the most useful available health indicators, together with data on economic

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factors and ethnicity. In addition, there is a series of reports on indicators for specific health issues, including alcohol, ethnicity and lifestyle factors, together with summaries of all indicators by region. APHO also did some work on disease prevalence models for hypertension and coronary heart disease to inform planning in 2007/08.

The Public Health Observatory Handbook of Health Inequalities Measurement³ and the Health Poverty Index⁴ provide further useful information.

The 'scarf' charts⁵ provide information on the relative contribution of cancer to excess deaths. The Health Inequalities National Support Team/NCAT 'How to' *Guide for Health and Wellbeing Boards*⁶ includes examples of the use of this information.

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- 3 Carr-Hill R and Chalmers-Dixon P (2005) The Public Health Observatory Handbook of Health Inequalities Measurement. Oxford: South East Public Health Observatory. www.sepho.org.uk/Download/Public/9707/1/Carr-Hill-final.pdf
- 4 www.hpi.org.uk
- 5 www.lho.org.uk/searchResults.aspx?st=scarf&os=0
- 6 www.ncat.nhs.uk/our-work/improvement/equality

2.2 Key commissioning questions

Key commissioning questions for needs assessment	Where to find the answers
What is the all-age all-cause mortality rate in your PCT?	Public Health Observatory/local public health network
What is the mortality from all cancers at age <75?	Public Health Observatory/local public health network
What is the mortality from all cancers at age >75?	Public Health Observatory/local public health network
What is the healthy life expectancy at age 65?	Public Health Observatory/local public health network
What is the prevalence of smoking among those aged >16?	Public Health Observatory/local public health network
What proportion of the local population is age >65, and what proportion is age >75?	Public Health Observatory/local public health network
What percentage of the population is employed?	Public Health Observatory/local public health network
What percentage of the population is on benefits?	Public Health Observatory/local public health network
What is the ethnic mix of the population?	Public Health Observatory/local public health network
Which are your more deprived wards?	Public Health Observatory/local public health network
How good are public transport links to your local cancer unit and centre – especially from more deprived communities and areas with high concentrations of older people?	Local knowledge

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2.3 Cancer Commissioning Toolkit metrics

The CCT contains the following metrics that relate to this chapter. These can be found by accessing the corresponding chapter, **Cancer landscape**, and the sections **The challenge of cancer** and **Cancer prevention**, either via the dashboard or the contents page.

2.3.1 The challenge of cancer

- Age standardised incidence rates
- New cancer cases
- Trends in cancer incidence
- Number of cancer deaths
- Five year rolling age standardised mortality rates
- Trends in five year rolling age standardised mortality rates
- % change in mortality rates since 1997
- Trends in % change in mortality rates since 1997
- One year survival estimates benchmarked
- Five year relative survival estimates benchmarked
- Trend in survival.

2.4 Planning checklist

The Operating Framework for the NHS in England 2011/12 sets out a number of areas that DH will not need to see in plans but which will require Strategic Health Authority (SHA) assurance that they are being addressed by commissioners. For the full Operating Framework, go to: www.dh.gov.uk/en/ managingyourorganisation/Financeandplanning/ Planningframework/index.htm

2.4.1 Cancer reform

- Implement Improving Outcomes: A Strategy for Cancer. In particular:
 - consider the four priority areas for diagnostics for improving earlier diagnosis of cancer (chest X-ray, non-obstetric ultrasound, flexi sigmoidoscopy/colonoscopy and MRI brain) and ensure that continuity of commissioning and provision is secured during transition to new commissioning arrangements
 - develop local plans to ensure that access rates to radiotherapy and the use of advanced radiotherapy techniques, such as intensity modulated radiotherapy, image guided radiotherapy and proton beam therapy, are appropriate for their populations
 - work with cancer networks to plan full implementation of NICE Improving Outcomes Guidance for cancer (particularly upper gastrointestinal, urological, head and neck and haematological)
 - ensure that providers include staging information in their cancer registration dataset in order to provide data needed to assess whether progress is being made on improving survival rates through earlier diagnosis (4.3 of the IOSC).

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2.4.2 Cancer screening

 Work with local services and NHS Cancer Screening Programmes to implement human papilloma virus (HPV) testing as triage for women with mild or borderline results (4.24 of the IOSC).

2.4.3 End of life care

- Ensure implementation of the *End of Life Care Strategy* (DH, 2008) – promoting high quality care for all adults at the end of life by:
 - ensuring that staff are trained to offer patients the choice of where to be cared for as they approach the end of life and where to die, including using the e-learning modules available as part of blended learning
 - ensuring that adequate 24/7 community services are available in their locality (*End of Life Care Strategy* (DH, 2008), pages 91 and 92, 4.33 and 4.34).

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3. Prevention

3.1 New and changing services

For the NHS to be sustainable in the 21st century it needs to focus on improving health as well as treating sickness. Our longer life span, the changing nature of disease and people's expectations are challenging the NHS to focus on its contribution to the prevention of ill health. In the consultation for the NHS Next Stage Review and the Next Stage Review final report, *High Quality Care for All*, nearly a quarter of people felt health was 'mainly my responsibility', and a further 60% felt it was 'mainly me with support from the NHS'.

We need to ensure that people have convenient access to prevention services – and that these are provided on 'an industrial scale'.

3.1.1 Stop Smoking services and tobacco control

Smoking is the single biggest preventable risk factor for cancer. Cigarette smoking has been causally linked with the development of an ever-increasing list of cancers, including lung, oral cavity, pharynx, oesophagus, pancreas, bladder, renal pelvis, nasal cavities and nasal sinuses, stomach, liver, kidney, uterine cervix and myeloid leukaemia.¹ Of the 4,000+ chemicals that are known to make up cigarette smoke, at least 40

are carcinogenic. However, there is also a growing body of evidence that not only does cigarette smoke initiate tumour development, but it may also promote tumour progression.^{2,3} In 2009, it is estimated that 29% (37,500) of all cancer deaths were attributable to smoking. This includes 82% of deaths from trachea, lung and bronchus cancer, 68% of deaths from cancers of the oesophagus and 66% of deaths from cancers of the upper respiratory sites.⁴ All the main smokingrelated diseases, including cancer, are responsive to stopping smoking.

A Smokefree Future: a comprehensive tobacco control strategy for England (DH, 2010), establishes a vision of eradicating tobacco harms and creating a smokefree future, to support people to live healthier and longer lives. The strategy sets out three overarching objectives to make significant progress towards a smokefree society:

- to stop the inflow of young people recruited as smokers
- to motivate and assist every smoker to quit
- to protect families and communities.

Against each objective, an aspiration has been set of what could be achieved by 2020, including halving the numbers of adult smokers to just 1 in 10, and reducing

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Print this page Print this section to negligible levels the number of children who take up smoking. Please follow this link for the full text: www. dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/DH_111749

Stop Smoking support from the NHS is available to all smokers free of charge in all communities across England. Smokers who use NHS support are up to four times more likely to quit successfully than those trying to go it alone ('cold turkey'). Advice and support for quitting are also available to smokers through NHS helplines and websites. Over 373,000 people successfully quit using NHS Stop Smoking services in 2009/10.

The blueprint for the service is based on extensive research evidence. However, much more needs to be done to improve the impact of the treatment provided; to increase the range of approaches to be used to support smoking cessation for all groups of people and the settings in which treatment can be provided; and to ensure that anyone who wants support in quitting has equal access to the most appropriate treatment. Currently, some 8% of smokers report that they use the NHS Stop Smoking service each year, but 25% of all those who successfully quit do so via this route, as it is the most effective method for quitting (four times more effective than quiting without support).

3.1.2 Weight management services

Obesity is a major risk factor for cancer and with 60% of adults overweight or obese, supporting and enabling individuals to lose weight and prevent weight regain is an important public health issue. Preventative and management services can provide vital support to individuals at risk of gaining weight or classified as overweight or obese, helping them to reach and maintain a healthy weight.

In order to ensure that individuals get the support and care they need local areas may have developed and established an obesity care pathway, taking account of NICE guidance. These local care pathways will set out the various weight management services available and any associated eligibility criteria, which are often dependent on the individual's weight status and health needs. These services are commissioned by PCTs in line with NICE guidance, although the type of service may vary according to prevalence and the needs of the local population.

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3.1.3 Physical activity services

Physical activity is an independent risk factor for a number of cancers: a person physically active at the levels recommended by the Chief Medical Officer (CMO) has a 50% lower risk of colon cancer and 20% lower risk of breast cancer.⁵

New UK guidelines for the 'dose' of physical activity across the life-course for general health benefits, drawing upon the latest international evidence, will be published later this year. These will include advice on limiting sedentary behaviour.

Let's Get Moving is a national behaviour change intervention, available to the NHS and based on NICE public health guidance 2, 2006, which endorses brief interventions in physical activity as being both clinically and cost effective in both the short and very long term, and integrating NICE public health guidance 6, 2007, on behaviour change.

Let's Get Moving enables health professionals to identify adults not meeting the CMO's recommendations for physical activity for health, deliver a brief intervention and signpost on to local physical activity opportunities (*Let's Get Moving commissioning guidance*, DH 2009).

Community-based physical activity programmes, including volunteer-led walking schemes, can provide a safe and supportive environment for individuals to increase their physical activity levels.

Key commissioning questions for prevention	Where to find the answers
What is the current performance on the smoking cessation target for the PCTs? How does this compare with similar areas?	Information Centre for Health and Social Care – statistics on NHS Stop Smoking services
Are there any geographic or population groups with high rates of smoking? Are services available to meet their needs?	Local Director of Public Health reports or health equity audits
Are Stop Smoking services sufficient to meet the local needs?	General Lifestyle Survey; Smoking at Time of Delivery (SATOD); GP prevalence; tobacco profiles (currently published on the London Health Observatory website www.lho.org.uk)

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Key commissioning questions for prevention	Where to find the answers
Are other prevention services sufficient to prevent cancer?	
Does the incidence of skin cancer in your network or PCT warrant consideration of local investment in skin cancer prevention initiatives?	SunSmart resources (www.sunsmart.org.uk/) Guidance on how NHS and local authorities can help prevent skin cancer using public information, sun protection resources and changes to the environment, plus how healthcare services for people with skin tumours should be organised (http://guidance.nice.org.uk/CSGSTIM) Skin cancer profiles, showing trends in skin cancer indicators across different areas of England (South West Public Health Observatory skin cancer hub: www.swpho.nhs.uk/default.aspx?RID=59397)

3.1.4 Cancer Commissioning Toolkit metrics

- Stop smoking services and tobacco control
- Successfully quit smoking at four weeks, time trend (self-reporting)
- Percentage who successfully quit smoking at four weeks (self-reporting)
- Actual number setting quitting date and quitting smoking after four weeks, time trend
- Rate of smoking quitters per 100k population age >16 years, time trend.

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3.2. Cancer family history services NHS commissioning document

'We want people who are concerned about their family history of cancer to have access to cancer genetic services with high quality risk assessment and counselling services.' *Cancer Reform Strategy (paragraph 2.53)*

This section addresses cancer family history services – that is, services that triage patients based on their cancer genetic risk, managing patients from the receipt of referral through to determining an individual care pathway following risk assessment.

3.2.1 Background and key issues

Some people have an increased risk of cancer because they have a family history of cancer. It is well recognised that some families contain an above-average number of individuals with certain cancers, especially breast, ovarian and colorectal.

A proportion of these cancers is associated with inherited alterations in genes. Approximately 5–10% of breast, ovarian and colorectal cancer is thought to occur in individuals with single-gene mutations that confer a high genetic risk of that cancer.^{5,6,7} An additional proportion of these cancers is attributable to moderate (rather than high) genetic risk. In such cases, increased cancer incidence within a family is thought to be due to lower-risk inherited genes acting alone or interacting with environmental factors. It is estimated that moderate-risk familial clustering accounts for up to 20% of breast and colorectal cancer.^{8,9}

Those with a significant family history of cancer are more likely to develop cancer themselves, and to be affected at a younger age than the general population. Hence, they need to have appropriate risk assessment and be offered risk-reducing management. Indeed, demand for such risk assessment and management services has greatly increased in recent decades.

However, a number of issues have emerged. The *NHS Cancer Plan* acknowledged that cancer family history services were poorly developed. Referral rates have varied greatly across geographic areas. Some services have developed ad hoc, with variability in patient pathways, staff training and skills, and links with specialist genetics services. Services have also been under-accessed by black and minority ethnic groups.

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Print this page Print this section 5/19 As a result, individuals at increased genetic risk have not always been robustly risk assessed – or indeed assessed at all. Others have been enrolled in clinical surveillance unnecessarily, which is expensive and sometimes invasive, and reduces capacity for those who need it.

This section is based on the outcomes of a cancer family history programme co-sponsored by DH and the charity Macmillan Cancer Support in 2004–07. A number of pilot services were set up that provided dedicated risk assessment and support. The services followed a common pathway:

- promotion of the service to health professionals and, in some cases, the public
- easy access to the service through health professional referral and sometimes patient self-referral
- risk assessment of patients based on cancer family history, according to agreed protocols
- classification of patients into high, moderate and general population risk (that is, at no greater genetic risk than a member of the general population), with clear pathways for each.

Agreed pathways were developed for patients. Generally:

- population risk patients were reassured and discharged, in clinic or by letter
- moderate risk patients were referred for clinical surveillance, such as mammography
- high risk patients were referred for clinical surveillance, and for genetic counselling or testing. (Counselling was sometimes provided by the pilot service.)

Pilot services were located in primary or secondary care, with non-genetic specialists trained to undertake genetic triage. All pilots worked closely with specialist genetics services for training and service development; some pilots were overseen by genetics staff. All pilots worked with primary care, secondary care and specialist genetics services to develop co-ordinated, consistent patient pathways and to raise awareness of their service.

As well as providing seamless, effective and user-friendly care, the pilots facilitated the most effective use of resources. Patients were enrolled in clinical surveillance only after robust risk assessment. Referral to specialist

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Print this page Print this section 6/19 genetics services was reserved for high risk patients, making best use of scarce specialist resources. Ensuring effective use of resources is key, given that service demand will continue to rise with greater understanding of genetics and as cancer incidence increases with the ageing population.

The service innovations of the pilots were a key element of the Cancer Reform Strategy's recommendations for improved cancer family history services.

3.2.2 Needs assessment and service review

Commissioning should be based on assessment and review of:

- 1. the level of service required, based on population need
- 2. current provision of cancer family history services
- 3. key elements of service planning and delivery for current or future services.

These three elements are addressed in order in the following Key commissioning questions section.

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3.2.3 Key commissioning questions

1. Level of service required

Key commissioning questions	Where to find the answers
What is the estimated level of service required, based on population need?	Current local/regional providers
 Estimating need for services like these is complex, 	 Knowledgeable about levels of service use
hence data sources listed to the right are only indicators. Robust data from service providers	Regional Genetics Service
(current or future) is essentialCurrent levels of service use provide some	 Knowledgeable about the regional population, and may also be a current service provider
indication of level of need. However, if gaps in current service provision are identified (see sections 2 and 3 below), service use may	Cancer network
 underestimate need These services are relatively specialised. Given the likely level of patient need, it may be helpful to 	 Experienced in planning cancer services, hence may have relevant knowledge
estimate need (and accordingly plan services) for a catchment population of 1 million (or more)	Estimates based on cancer incidence and risk
 These services need capacity for patients who will ultimately be assessed as population genetic risk (needing no further management), as well as patients anticipated to be at moderate or high risk 	 Further details are provided in 3.2.6: 'Family history, cancer incidence and cancer risk: figures to inform service planning for patient numbers' below.
	 Cancer incidence data is available through the Cancer Commissioning Toolkit (www.cancertoolkit.co.uk)

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2. Current provision of cancer family history services

Key commissioning questions	Where to find the answers
 Are services in place for the cancers for which an increased genetic risk is most common? The cancers for which an increased genetic risk is most common are breast, ovarian and colorectal Cancers for which an increased genetic risk is much less common include prostate, melanoma, gastric, kidney, pancreatic and sarcoma. Where there is a family history of such cases, advice from genetic specialists should be obtained 	Current local/regional service providers Regional Genetics Service • Knowledgeable about current provision of cancer family history services
 2. If there is more than one current service provider: Is there any unnecessary duplication in services? Is there any duplication or inequity in funding for services? Funding streams to consider include local and collaborative commissioning 	Current local/regional service providers Commissioning team

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3. Key elements of service planning and delivery – for current or future services

Key commissioning questions	Where to find the answers (current services)
 Are there robust clinical governance arrangements? These should include: criteria for referral to the service evidence-based, validated tools and guidelines for assessing and managing patients' risk guidelines for verifying family histories, including the use of cancer registries adherence to data protection, patient confidentiality and consent, including consent to access family members' medical records processes for consultation with genetic specialists regarding complex or unusual cases 	 Local/regional service providers Guidelines: NICE guidance on familial breast cancer (www.nice.org.uk/Guidance/CG41) British Society of Gastroenterology guidelines for colorectal cancer screening in high risk groups (www.bsg.org.uk/clinical-guidelines/endoscopy/ guidelines-for-colorectal-cancer-screening- in-moderate-and-high-risk-groups-update- from-2002.html) Other guidelines/tools for assessing risk: local cancer network Regional Genetics Service
 2. For the cancers for which an increased genetic risk is most common, are there accessible, well managed and co-ordinated patient pathways for assessing and managing risk? For breast and ovarian cancer risk, pathways should comply with NICE guidance on familial breast cancer The pathway for patients who are assessed at population risk and discharged should include support, including guidance on what to do if family history information changes 	Local/regional service providers NICE guidance on familial breast cancer (www.nice.org.uk/Guidance/CG41)

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Key commissioning questions	Where to find the answers (current services)
 3. What are the skills, training and support, including clinical supervision, that staff need to deliver the service? Roles and job descriptions should include relevant genetics competences linked to the NHS Knowledge and Skills Framework 	 Regional Genetics Service Knowledgeable about risk assessment processes and service delivery Local/regional service providers UK Workforce Competences for Genetics in Clinical Practice for Non-genetics Healthcare Staff (link in 3.2.7: 'Further information')
 4. To indicate whether services are reaching the right patients and managing them appropriately, is there ongoing review/audit of: risk assessment outcomes? onward referrals to (or service provision of) clinical surveillance and specialised genetics services? 	Local/regional service providers Regional Genetics Service
5. As an indicator of equity and accessibility, how do patient referrals and completed risk assessments compare to the patient population, in terms of factors including geographic location, ethnic origin and socioeconomic class?	Local/regional service providers Data on local/regional population is available through the Cancer Commissioning Toolkit (www.cancertoolkit.co.uk)
6. Are services in compliance with the risk assessment element of NICE guidance on familial breast cancer?	Local/regional service providers NICE guidance on familial breast cancer (www.nice.org.uk/Guidance/CG41)

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Key commissioning questions	Where to find the answers (current services)
7. Are patients given appropriate written information at each stage of the patient pathway?	Local/regional service providers
8. Regarding stakeholders in service delivery:	Local/regional service providers
 Have stakeholders been identified, including service users and healthcare professionals from primary and secondary care and specialised genetics services? To what extent are stakeholders involved in planning, delivering and reviewing services? Are regular patient experience surveys undertaken? 	Local Involvement Networks (LINks)

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3.2.4 Markers of Best Practice (quality indicators)

- Patients' risk is assessed and managed using evidence-based, validated tools and guidelines.
- Patients assessed at moderate and high risk, and at an appropriate age, are offered referral for clinical surveillance (where guidelines indicate referral).
- Patients assessed at high risk, and at an appropriate age, are offered referral for (or provided by the service with) genetic counselling or testing.
- Assessment of patients' risk of breast and ovarian cancer complies with NICE guidance on familial breast cancer.
- Patients with uncommon cancer syndromes are offered referral to specialised genetics services.
- Patients assessed at general population risk are offered advice on symptom awareness and reducing cancer risk.
- The extent to which patient referrals match the patient population, including for hard-to-reach groups, is kept under active review.
- Skills required by staff to deliver the service are included in role/job descriptions and reviewed annually.
- There is regular and systematic review of the level of patient satisfaction with the service.

3.2.5 Implications for other services

When reviewing existing services or planning new ones, implications for other services should be considered:

• **Regional genetics services:** There are regional genetics services across the UK providing specialist genetics services and advice. It is imperative that new cancer family history services should be established in conjunction with regional genetics services. Staff assessing cancer risks and communicating risk information to patients will need to be trained and closely supervised. Regular update of staff by genetics services is also essential to ensure that the most up-to-date risk assessment tools are used and current information and advice are given about risk management and clinical surveillance. Regional genetics services will need to be involved at the early stages of establishing new cancer family history services and although the cost of regional genetics services is commissioned by specialist genetics commissioning, the impact on the regional genetics service in terms of training, supervision, increased genetics referrals and the potential increase in numbers of genetic tests also needs to be considered and discussed.

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- Clinical surveillance: Addressing gaps in existing family history services, in terms of cancers covered or the population reached, is likely to generate additional referrals for clinical surveillance. Most of these additional referrals would be for mammography or colonoscopy.
 - Estimated take-up of mammography among women at moderate risk of breast cancer: for a population of 1 million people, over a 10 year period, assuming a take-up rate of 50%, approximately 950 women aged 40–49 at moderate risk of breast cancer could be expected to take up annual mammography.¹⁰
 - Magnetic Resonance Imaging (MRI) for women at high risk of breast cancer: women who have been assessed at high genetic risk of breast cancer should have access to MRI, in accordance with NICE guidance on familial breast cancer.
 For a population of 1 million people, up to approximately 75 high risk women could be expected to take up annual MRI scanning, depending on these women's decisions about other risk-reduction management.¹¹
 - The NHS Breast Screening Programme takes responsibility for managing surveillance for women at high risk of breast cancer. NHS Cancer Screening Programmes are piloting the new arrangements in two screening sites, and advice to the NHS will be issued in due course.

 If required, additional capacity for clinical surveillance may be found through reviewing patients currently enrolled in surveillance following genetic risk assessment. Have these patients been enrolled on the basis of robust risk assessment and up-to-date family history information?

3.2.6 Family history, cancer incidence and cancer risk: figures to inform service planning for patient numbers

Family history, cancer incidence and cancer risk Breast, ovarian and colorectal cancer incidence and genetic risk:

- High risk: Approximately 5–10% of breast, ovarian and colorectal cancer is thought to occur in individuals with inherited single-gene mutations that confer a high genetic risk of that cancer.^{9,10,11} The figure for ovarian cancer is generally higher than for breast and colorectal cancer. (The lower limit for colorectal cancer may be below 5%.⁷)
 - Lifetime risk: Lifetime risks of cancer are high for individuals with genes that confer high genetic risk. For instance, for women who are carriers of the breast and ovarian cancer predisposing genes BRCA1 and BRCA2, lifetime risks can be up to 80% for breast cancer and up to 60% for ovarian cancer.¹⁰ For colorectal cancer, depending on which gene is involved, lifetime risk can be up to 85% or even be virtually 100%.⁵

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- Moderate risk: An additional proportion of breast, ovarian and colorectal cancer is attributable to moderate (rather than high) genetic risk. In such cases, increased cancer incidence within a family is thought to be due to inherited genes, acting alone or interacting with environmental factors. It is estimated that moderate risk familial clustering accounts for up to 20% of breast and colorectal cancer.^{8,9}
- Lifetime risk: Lifetime cancer risk for those assessed at moderate risk of breast, ovarian or colorectal cancer is generally at least twice the general population risk.^{11,12,13} (See opposite for general population risks.)

Breast cancer and risk for relatives:

For approximately 15–20% of women with breast cancer, their first-degree relatives (sisters, daughters) would be assessed at moderate risk of breast cancer according to the NICE guidelines. This is because:

- 10–15% of women with breast cancer have a first or second degree relative with breast cancer.¹³ Therefore, the first degree relatives (sisters, daughters) of these 10–15% of patients would be in the moderate risk category, with two relatives with breast cancer.⁸
- Approximately 5% of breast cancer is diagnosed in women under the age of 40.⁸ Therefore, first degree relatives of these 5% of patients would also be in the moderate risk category.⁸

Family history and cancer risk within the general population Family history and risk of breast cancer:

• The NICE guidelines provide an estimate that 'for a total population of 1 million with an age and sex structure comparable to that of England and Wales there would be 20–40 families whose family history of breast cancer would indicate that members had a high risk of developing breast cancer (R&D Office of Anglia and Oxford 1998). Furthermore, 4,450 women aged 35–49 would be estimated to be at moderate risk of developing the disease, out of a total of 47,000 women at risk.'⁸

Family history and risk of colorectal cancer:

 Approximately 0.5% of the general population aged 40–75 would meet British Society of Gastroenterology criteria for moderate risk surveillance management.¹⁶

Estimated lifetime cancer risks within the general population (UK data) 13

- Breast cancer risk: 1 in 8 women
- Colorectal cancer risk: 1 in 16 men, 1 in 20 women
- Ovarian cancer risk: 1 in 50 women

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For information purposes only – risk assessment outcomes in the Department of Health/Macmillan cancer family history programme For patients referred (via health professional or selfreferral) who had a completed risk assessment: across the pilot services, an average of:

- 32% of patients were assessed as general population risk (range 17–47% within individual pilots)
- 39% of patients were assessed as moderate risk (range 13–44%)
- 29% of patients were assessed as high risk (including some referred onward for specialist genetics assessment) (range 11–60%).

3.2.7 Further information

Resources for service development:

Resources for developing cancer family history services are available through the NHS National Genetics Education and Development Centre, www.geneticseducation.nhs.uk. Resources include:

• UK Workforce Competences for Genetics in Clinical Practice for Non-genetics Healthcare Staff, www.geneticseducation.nhs.uk/media/16686/ Competence_Framework.pdf

- Genetics in Mainstream Healthcare: A toolkit for developing services, www.geneticseducation.nhs. uk/genetics-in-practice/developing-services-andnew-roles/a-toolkit-for-developing-new-services. aspx. The toolkit was developed from Department of Health sponsored service development initiatives, including the Department of Health/Macmillan cancer family history programme
- The Experiences and Preferences of People Receiving Genetic Information from Healthcare Professionals (2007), www.geneticseducation.nhs. uk/media/16215/genetics_experiences_report.pdf

The Centre's website also has information about genetics education for health professionals – including learning outcomes for training programmes, as well as the agreed competencies as indicated above.

Guidelines for referral to cancer family history services:

Sample guidelines are available at: www.macmillan.org.uk/Aboutus/Healthprofessionals/ Cancer_genetics/Cancer_genetics_programme/Pilot_ services/Referral_guidelines.aspx

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Department of Health/Macmillan cancer family history programme resources:

These include an overview of how individual pilot services were delivered, resources about the role of service users in the programme and the individual pilots, and the pilots' final reports,

www.macmillan.org.uk/genetics-programme

• The journal *Familial Cancer* (www.springerlink.com/content/105711/) published a special edition about the programme

in June 2007 (volume 6, no. 2)

Patient information material about genetics and cancer:

Available from Macmillan Cancer Support, www.macmillan.org.uk/Cancerinformation/ Causesriskfactors/Genetics/Genetics.aspx

Booklets available are *Cancer Genetics – How cancer* sometimes runs in families and *Understanding Risk*reducing Breast Surgery. There are also leaflets for people who may be concerned about cancer in their family: a general leaflet *Are You Worried About Cancer*, and specific leaflets about breast, ovarian, bowel and prostate cancer. • The www.macmillan.org.uk/genetics website includes a link to OPERA, an online risk assessment tool for people worried about the occurrence of breast and/or ovarian cancer in their family.

Education and training:

Resources to support GPs and other healthcare professionals who refer patients to cancer family history services include:

- Cancer and genetics: an up to date guide an e-learning module freely available at BMJ Learning, www.learning.bmj.com/cancergenetics (free access, short registration form required)
- 'Learning genetics' section of the NHS National Genetics Education and Development Centre website, www.geneticseducation.nhs.uk. This covers topics such as taking a family history, patterns of inheritance and communicating genetic information
- NHS Evidence (www.evidence.nhs.uk) has a range of resources to support healthcare professionals who need genetic information for themselves and their patients.

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Policy documents:

- Cancer Reform Strategy (2007), www.dh.gov. uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/dh_081006
- Genetics White Paper, Our Inheritance, Our Future: Realising the potential of genetics in the NHS (2003), http://webarchive.nationalarchives.gov. uk/+/www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/ DH_4006538
- Genetics White Paper Progress Review (2008), http://webarchive.nationalarchives. gov.uk/+/www.dh.gov.uk/en/Publichealth/ Scientificdevelopmentgeneticsandbioethics/ Genetics/DH_084147

User involvement in planning and developing services:

Addressed in various resources, including:

- Real Involvement: Working with people to improve health services (2008), www.dh.gov. uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/DH_089787
- All Department of Health/Macmillan pilots involved service users in developing services, and service users also had a prominent role in the programme as a whole. Resources about service user involvement are available at: www.macmillan.org.uk/Aboutus/ Healthprofessionals/Cancer_genetics_programme/ Pilot_services/serviceuserinvolvement.aspx

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- 8 McIntosh A, Shaw C, Evans G et al (2004; updated 2006) *Clinical Guidelines and Evidence Review for the Classification and Care of Women at Risk of Familial Breast Cancer*. London: National Collaborating Centre for Primary Care/University of Sheffield. NICE guidelines CG41 (full guideline). Estimated proportion of breast cancer attributable to moderate risk on page 147, estimated numbers of high and moderate risk women in a population of 1 million on page 19. www.nice.org.uk/guidance/index.jsp?action=download&o=30253
- 9 Cancer Research UK website, accessed 16/02/10. info.cancerresearchuk.org/cancerstats/types/bowel/molecularbiologyandgenetics/?a=5441 Dove-Edwin et al (reference 5) estimate that 'Moderate familial clustering accounts for about a third of colorectal cancer but represents a heterogeneous group attributable to a combination of genes, environment and chance'.
- 10 Estimates of mammography and MRI take-up rates are from personal communication with Professor Gareth Evans, 2008–2009.
- 11 Moderate risk of breast cancer is defined in the NICE guidelines (reference 4, page 24) as a lifetime risk of 17% or higher but less than 30%, compared with a general population lifetime risk of 11%.
- 12 Surveillance is recommended for colorectal cancer when an individual's lifetime risk is at least 10% (Lalloo F (2005) Risk estimation in colorectal cancer. In: Lalloo F, Kerr B, Friedman J, Evans G (Eds.) *Risk Assessment and Management in Cancer Genetics* (pp. 65–72). Oxford: Oxford University Press).
- 13 Women have an increased risk of ovarian cancer if they have a first-degree relative with ovarian cancer (Pharoah P, Ponder B (2004) Familial ovarian cancer: genetics and management. In: Eeles R, Easton D, Ponder B, Eng C (Eds.) *Genetic Predisposition to Cancer*, 2nd edition (pp. 303–314). London: Arnold). However, for ovarian cancer, there is currently no routine clinical surveillance to offer women, and risk management (surgery) is generally offered only to women who have been assessed at significantly increased risk. The NICE guidelines (reference 4) recommends referring women onward from primary care only if their family history indicates that they may be at significantly increased risk of ovarian cancer.
- 14 Kerr B (2005) How to evaluate a family history. In: Lalloo F, Kerr B, Friedman J, Evans G (Eds.) *Risk Assessment and Management in Cancer Genetics* (pp. 3–12). Oxford: Oxford University Press.
- 15. Cancer Research UK, website accessed 16/02/10. www.cancerhelp.org.uk/type/breast-cancer/about/should-i-see-a-breast-cancer-specialist
- 16. Dunlop MG (2002) Guidance for large bowel surveillance for people with two first degree relatives with colorectal cancer or one first degree relative diagnosed with colorectal cancer under 45 years. *Gut* 51(Suppl V): v17–v20. www.bsg.org.uk/clinical-guidelines/endoscopy/guidelines-for-colorectal-cancer-screening-in-moderate-and-high-risk-groups-update-from-2002.html

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4. Diagnosing cancer earlier: awareness, early detection and screening

4.1 Introduction

In general, the earlier a cancer can be diagnosed the greater the prospect of survival. England has poor survival rates for a number of cancers when compared internationally. It has been estimated that 10,000 deaths could be prevented each year by bringing survival rates in England in line with the best in Europe.¹ The majority of these deaths are likely to be due to late diagnosis.² The most recent analysis compares survival from colorectal, lung, breast and ovarian cancer in the six countries participating in an International Cancer Benchmarking Project. For patients diagnosed between 1995 and 2007, it shows that survival has continued to improve for each cancer in all six countries, but generally remains higher in Australia, Canada and Sweden, intermediate in Norway, and lower in Denmark and the UK. The patterns are consistent with diagnosis at a later stage or differences in treatment, particularly in Denmark and the UK and in older patients.³

While some cancers (breast, cervical and bowel) can be detected early by screening, most cancers cannot be screened for, and so improvements must come from symptomatic diagnosis. Public awareness of the main cancer risk factors and knowledge of the signs and symptoms of cancer (other than a lump) is poor in England, especially among deprived populations and black and minority ethnic groups, and it is probable that this leads to patients presenting later with possible cancer symptoms.

4.1.1 Improving Outcomes: A Strategy for Cancer

(IOSC) commits to saving an additional 5,000 lives every year by 2014/15, narrowing the inequalities gap at the same time.

Preventing people from dying prematurely is the first of five domains in *Transparency in Outcomes* – *A framework for the NHS* (DH, 2010) www.dh.gov.uk/ en/consultations/liveconsultations/DH_117583. Cancer is identified in domain 1 as a specific improvement area, given that international evidence suggests that there is scope for improvement.

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- Abdel-Rahman M, Stockton D, Rachet B et al (2009) What if cancer survival in Britain were the same as in Europe: How many deaths are avoidable? British Journal of Cancer 101(Suppl 2): S115–S124.
- 2 Richards MA (2009) The size of the prize for earlier diagnosis of cancer in England. *British Journal of Cancer* 101(Suppl 2): S125–S129.

3 Coleman MP, Forman D, Bryant H et al (2011) Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* 377(9660): 127–38.
To achieve earlier diagnosis there is a need to:

- raise public awareness of cancer signs and symptoms, and encourage earlier presentation to primary care
- support GPs to assess patients effectively and, where appropriate, refer them urgently
- improve GP access to diagnostic tests to help them to confirm or exclude a diagnosis of cancer.

4.1.2 Roles and responsibilities

The achievement of priority NHS and public health outcomes related to cancer will need commissioners working with health and wellbeing boards to:

- have the right information from
 - patients their knowledge, attitudes and experience of cancer: National Cancer Patient Experience Survey
 - cancer data: National Cancer Intelligence Network (NCIN); Cancer Commissioning Toolkit (CCT)
 - outcome and process measures linked to cancer and early diagnosis: GP practice profiles and commissioner profiles; any local audits of cancer diagnosis in primary care (www.dur.ac.uk/school.health/erdu/cancer_audit/)

- the local community: PCT profiles (with plans for local authority/health and wellbeing board cancer profiles)
- understand local diagnosis, treatment and care for cancer patients through knowledge of:
 - key providers in public health, primary care and secondary care, as well as services delivered by the voluntary sector and other independent providers
 - patient pathways for common and rare cancers (Map of Medicine care maps)
 - the local cancer network, including Network Site Specific Groups.

Commissioners working with health and wellbeing boards will need to establish and sustain programmes of work. This may require a range of approaches, from public awareness campaigns to system changes in primary and secondary care, to deliver improvements that will achieve earlier diagnosis of cancer. Programmes will need effective clinical leadership (public health and general practice, working closely with hospital clinicians), and be of sufficient scale to improve outcomes in cancer survival.

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4.2 Planning and commissioning

The Joint Strategic Needs Assessment (JSNA) will be an opportunity to include the key measures to understand the local position and needs, as follows:

- the level of mortality amenable to healthcare including cancer
- one year and five year cancer survival rates
- mortality from cancer by age
- the number of patients with cancer diagnosed following an emergency presentation [Note: Work in progress to collect this data centrally]
- patients with cancer diagnosed at stage 1 and 2, as a proportion of cancers diagnosed [Note: Work in progress to improve coverage and consistency of staging data]
- the inequality gaps between different groups and areas
- active treatment rates.

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Key commissioning questions for awareness and early detection	Where to find the answers
What are the one year and five year survival rates for breast lung and colorectal cancer patients?	National cancer registries
How does this compare to the European average and international good practice benchmarks?	Public Health Observatories
	Office for National Statistics
	ССТ
	For good practice benchmarks see the <i>Cancer Reform Strategy</i> second annual report
What is the level of symptom awareness of people? How does this compare with national level data?	National Cancer Awareness Measure (CAM), CAM data repository (many cancer networks have completed CAM surveys, and the results are similar – there is likely to be data available for a similar population)
Has there been an assessment of cancer incidence?	NCIN Cancer Information Service
Has there been an assessment of cancer mortality?	NCIN Cancer Information Service, which includes:
	 mortality analysis by locality relative change in mortality rates and level of change in mortality rates since 1997 compared with England

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Key commissioning questions for awareness and early detection	Where to find the answers
Has there been an assessment of inequalities by age, socioeconomic background or ethnicity for mortality	NCIN Cancer Equalities Portal: www.ncin.org.uk/equalities/
	NCIN mortality analysis by PCT
	Public Health Observatories
What are the two week wait referral rates by general practice per 10,000 population? How does this compare with national averages? What is the variation between general practices?	Practice and PCT profiles available through the CCT operational standards database, local analysis. Practice information is available from cancer network GP leads
What proportion of cancers is diagnosed through the non-urgent route (excluding screening)? How does this compare with other commissioners?	Practice and PCT profiles available through the CCT. Practice information is available from cancer network GP leads
	Cancer Waiting Times Database, local analysis
What proportion of cancers is diagnosed through emergency presentations? How does this compare	NCIN Routes to Diagnosis briefing
with two week wait referrals?	ССТ
What are the views of local patients about their diagnosis and the effectiveness of referral from general practice to specialist services?	DH National Cancer Patient Experience Survey Programme – 2010 national survey report
Is there reliable staging data available for any cancers? What does this show about stage at diagnosis?	Cancer registries

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4.2.1 Changing the public's behaviour around early presentation

Commissioners working with health and wellbeing boards will need to consider new ways to increase public and professional awareness of the signs and symptoms of cancer and encourage earlier presentation across the whole population. There is a need to encourage a cultural shift so that people visit their doctor promptly when they do suspect cancer. There is a need particularly to target the over-50s and recognise that lack of symptom awareness applies to all socioeconomic groups, but is more acute in disadvantaged groups.

The national **Cancer Awareness Measure** (CAM) survey showed low levels of awareness for cancer symptoms other than a lump, and highlighted a number of potential barriers to presentation. Local surveys have confirmed these findings, and all CAM data is available online (www.esds.ac.uk/newRegistration/ newLogin.asp). In addition, DH and Cancer Research UK have commissioned **qualitative research** to further explore the barriers to early presentation, as well as investigating how to motivate people with potential signs and symptoms of cancer to visit their GP quickly (www.naedi.org).

Evidence on the best ways to raise awareness of cancer symptoms and translate this into earlier appropriate

presentation to primary care is still emerging. There are a range of interventions which draw on social marketing models and theory for behaviour change. These include campaigns, community outreach or volunteer-led initiatives, one-to-one education delivered by health professionals, and using existing health and social care services and activities. Working in collaboration with the National Social Marketing Centre, the DH Cancer Team has produced a cancer Social Marketing Planning Guide and Toolbox (www.socialmarketing-toolbox.com).

The DH has piloted a bowel cancer signs and symptoms and public awareness campaign in 2011 in two regions of the country. Public Health England will be responsible for a range of services relevant to cancer – all of which will be important in achieving improved outcomes, including targeted campaigns to raise public awareness of symptoms and to encourage early presentation. In 2010/11, DH allocated funding across 109 PCTs to implement and evaluate local early diagnosis initiatives.

Public health leadership is needed to ensure accurate targeting and rigorous evaluation of interventions, and co-ordination with other public health initiatives. Commissioners will want to work with their public health leads to understand their population, identify the best ways to change their behaviour and commission services accordingly, keeping up to date with emerging evidence.

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Significant work has already been undertaken through the National Awareness and Early Diagnosis Initiative (NAEDI) to test local interventions. Learning is being captured and disseminated. For example:

- The Doncaster Cough Campaign for lung cancer achieved an increase in the number of people seeing their GP and an increase in patients diagnosed at an earlier stage of lung cancer from 11% to 19%. A 'How to' guide has been produced to share all the stages of the development, funding, delivery, evaluation, roll-out and embedding of the approach. A number of commissioners are currently applying this model and evaluating the impact in their areas.
- Community outreach methods, such as those used and evaluated in the Healthy Communities Collaborative.⁴

For more details, see www.naedi.org.

4.2.2 Early detection of cancer by primary care professionals

GPs see only around eight or nine new cases of cancer each year. However, they see many more patients presenting with symptoms that could be cancer – and those symptoms are generally symptoms of many other diseases as well. This therefore makes it difficult for GPs to assess when it is appropriate to refer patients on to secondary care for investigation. Commissioners should consider the following data sources for insight into the challenges faced by primary care:

- Practice/PCT profiles provide comparative activity information against outcome and process measures in primary care that are relevant to cancer and early diagnosis. They are not a performance management tool, but are intended to get primary care engaged and thinking about clinical practice and service delivery in this area. A system has been put in place to make this data available to GPs. More information is available from the NCIN website or the cancer networks.
- The Royal College of General Practitioners National Audit of Cancer Diagnosis in Primary Care (www.dur.ac.uk/school.health/erdu/cancer_audit/) provides insight into the routes to diagnosis of cancer patients in primary care, and the intervals experienced by cancer patients. National reports will be available during 2011, and local reports are available from the cancer networks that have taken part in the audit. As part of the National Audit of Cancer Diagnosis in Primary Care, two significant event audits have been completed –

4 Lyon D, Knowles J, Slater B and Kennedy R (2009) Improving the early presentation of cancer symptoms in disadvantaged communities: Putting local people in control. *British Journal of Cancer* 101(Suppl 2): S49–S54.

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for lung cancer, and teenage and young adult cancer – which provide insight into the issues in those particular areas. A further two significant event audits are being carried out, for ovarian and upper gastrointestinal (GI) cancers.

- A national study supported by NCIN used existing routinely available data sources to review patients' cancer journey and examine the sequence of events that took them to diagnosis. These routes to diagnosis included both inpatient and outpatient attendance, screening and emergency presentation. The analysis shows the proportion of patients diagnosed through each route and the corresponding survival rates. There is wide variation across different cancer types in routes to diagnosis. Across all cancers, 25% of patients are being diagnosed through the two week wait, while 23% are presenting as emergencies. Opportunities to carry out local analyses and comparison of this information with national data will give insight into how investigative and referral practices might need to change in order to improve the number of cancers diagnosed quickly. Analysis of national routes to diagnosis is published on the NCIN website.
- The National Patient Safety Agency (NPSA) thematic review of delayed diagnosis of cancer made a number of recommendations to improve diagnosis of cancer in primary and secondary care and is available at: www.nrls.npsa.nhs.uk/ resources/?EntryId45=69894. It makes five broad recommendations, one of which is particularly relevant to primary care commissioning: 'Develop a model for stronger leadership and improved patient safety reporting and learning, including Significant Event Audit (SEA), at a local and national level.' The NPSA has indicated that it will continue to work to improve reporting, for example by developing a national, standardised SEA pro forma.

A range of guidance and tools to aid GPs in detecting and diagnosing cancer earlier are being developed and will be widely promoted:

 A GP Bowel Cancer Resource Pack has been produced and provides additional support to GPs, including regional information about bowel cancer, information about urgent and non-urgent referrals and the NHS Bowel Cancer Screening Programme. The pack can be downloaded from www.bowelcanceruk.org.uk/home/bowel-cancer/ downloads/gp-pack.

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- Decision support tools, risk assessment, safetynetting practices, audit and consultation practices are all being developed, and integrating these into GP training, appraisal and revalidation is being considered.
- There are some practical examples where GP leads are introducing cancer awareness and early diagnosis into general practice (for example, http:// info.cancerresearchuk.org/spotcancerearly/naedi/ local-activity/getting-results/clinical-leadership/gpleadership/), as well as:
 - a service improvement initiative in the North of England that resulted in improvements in the lung cancer diagnosis pathway
 - a DVD and training resource developed for GP registrars by the North London Cancer Network GP lead
 - a training resource for health and social care staff being tested in the Lancashire and South Cumbria Cancer Network.
- Learning sets on engaging GPs in cancer awareness and early diagnosis, including case studies from four cancer network GP leads, are available from NCAT.

4.2.3 Clinical leadership for early diagnosis

Clinical leadership is a key part of leading and managing change in the way that primary care professionals manage patients with potential cancer symptoms. GP leads in cancer networks are supporting practices to

review the GP practice profiles and target the use of the primary care audit, and are supporting national and local public awareness initiatives. GPs are working closely with public health consultants and secondary care clinicians.

Commissioners should consider:

- supporting local practices to understand clinical and health outcomes linked to early diagnosis of cancer and identify practical ways to tackle variations, e.g. practice profiles
- helping GPs to identify, monitor and demonstrate good practice, as well as indicating where improvement should be targeted and service changes made, e.g. using audit tools to review cancer diagnoses in primary care
- disseminating learning and evidence of interventions that promote earlier diagnosis in primary care, drawing on a clinical evidence base and evidence around systems management to identify best practice and optimum care pathway change programmes
- helping to set appropriate objectives and metrics to review clinical and health outcomes, using the comparative practice profiles and other information, such as the local outputs from the National Cancer Diagnosis in Primary Care audit and baseline assessments for early diagnosis work to set the context
- assessing the quantifiable impact of introducing service changes on patient outcomes.

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4.2.4 Access to diagnostics

The Operating Framework for the NHS in England 2011/12 has asked commissioners and providers to consider the four priority areas for diagnostics for improving earlier diagnosis of cancer:

- chest X-ray: to support diagnosis of lung cancer
- non-obstetric ultrasound: to support diagnosis of ovarian cancer
- flexi sigmoidoscopy/colonoscopy: to support the diagnosis of colorectal cancer
- MRI brain: to support diagnosis of brain cancer.

Guidelines to support GPs and commissioners will be developed. The DH will also ensure that data is routinely collected about GP usage of tests, so that this can be used for benchmarking purposes. It will be the role of commissioners to commission additional direct access tests.

4.2.5 Understanding the costs and benefits of early diagnosis

The stage of diagnosis is likely to have an impact on the potential for successful treatment, on patient outcomes, and on resources. The DH commissioned a modelling exercise to examine the impact that earlier detection and diagnosis would have on survival curves and on downstream costs and benefits. The report, *The Likely Impact of Earlier Diagnosis of Cancer on Costs and Benefits to the NHS*, is available at: www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/ DH_123371

The specific questions addressed by this piece of work are:

- How would the costs to the NHS change if certain cancers (see below) were detected and diagnosed appreciably earlier than is currently the norm?
- How would the benefits to individuals change if certain cancers (see below) were detected and diagnosed appreciably earlier than is currently the norm?

The work focused on five cancers: breast, colorectal, lung, prostate and skin (melanoma).

Increasingly, local initiatives, such as the Doncaster Cough Campaign, are sharing their budgets, both for comparison with other initiatives and to enable cost benefit analysis.

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4.3 Working with cancer networks

Commissioners will need to ensure that sustainable programmes of work and service change are being implemented. Programmes will need effective clinical leadership (public health and general practice, working closely with hospital clinicians), and be of sufficient scale to achieve outcomes.

Most cancer networks have established groups to bring together clinical and programme expertise on awareness and early diagnosis. They will have valuable experience and information for health and wellbeing boards and commissioners.

The National Cancer Action Team (NCAT) is supporting a national programme of awareness and early diagnosis learning sets, focusing on commissioning, sustainability and engagement with general practice. A report on key themes will be available in spring 2011. Early indications are that the key themes will be:

- information and support to GPs in both their provider and commissioner roles
- how to sustain and embed public awareness initiatives during the transition and establishment of public health in local government, working closely with charities and voluntary sector groups

 how to implement new ways of working to bring together public health and NHS services to achieve joint cancer outcomes, such as improved survival and mortality.

4.4 Breast cancer screening

The national computerised call/recall system for breast screening was introduced in 1988, the first such programme in the EU. Women aged 50–70 are invited for free breast screening every three years. Women over 70 can request free three-yearly screening. Breast screening by mammography is an X-ray examination of the breasts and can show breast cancers at an early stage, when they are too small to see or feel. If changes are found at an early stage, there is a good chance of a successful recovery.

The World Health Organization's International Agency for Research on Cancer (IARC) evaluated the evidence on breast cancer screening in March 2002. IARC concluded that trials have provided sufficient evidence for the screening of women between 50 and 69 years, and that the reduction in mortality from breast cancer among women who chose to participate in screening programmes was estimated to be about 35%. The IARC working group consisted of 24 experts from 11 countries. The NHS Breast Screening Programme

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(NHSBSP) in England saves an estimated 1,400 lives per year,⁵ and 97.2% of women who have had invasive breast cancer detected by screening are alive five years later.⁶

4.4.1 Coverage and uptake

The gold standard of measuring the effectiveness of the NHSBSP is coverage – the proportion of women resident and eligible at a particular point in time who have had a screening test recorded in the previous three years. Uptake is also recorded – the proportion of women invited for screening over a year for whom a screening test result is recorded. For the NHSBSP, uptake is a measure of response to invitations generated by the programme, while coverage measures the proportion actually screened, and includes timeliness of call and recall. Many breast screening services have experienced slippage in the three-yearly screening round since the last age extension, mainly due to a shortage of radiographic staff. This has reduced coverage. although uptake may remain high when women are eventually invited.

4.4.2 Extension of the programme

IOSC noted that the NHSBSP is currently being extended to women aged 47–49 and 71–73. *The Operating Framework for the NHS in England 2011/12* states that commissioners should ensure that all screening services continue to take part in the breast screening age extension randomisation project, either screening women aged 47–49 or 71–73, depending on the randomisation protocol.

The randomisation project, led by researchers at the University of Oxford, will give directly comparable mortality data on the effectiveness of screening, including the benefits and harms, in these populations. The results of the project will be of international importance and will show whether screening in the extended age ranges is effective or not. That is why the randomisation is being run over two three-year screening rounds rather than one. Full roll-out to women aged 47–49 and 71–73 is expected to be completed after 2016.

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5 Advisory Committee on Breast Cancer Screening (2006) Screening for Breast Cancer in England: Past and future.

6 British Association of Surgical Oncology (2009) Surgical Guidelines for the Management of Breast Cancer.

In combination with the age extension, local breast screening programmes are replacing their current film systems with digital systems (direct digital mammography). Programmes have been advised to move to direct digital mammography as quickly as possible, as the independent Advisory Committee on Breast Cancer Screening has said that running both film and digital systems together is inefficient.

Funding of the extension is being managed by NHS Cancer Screening Programmes, and in order for them to release the funding to local screening units the following criteria need to be met:

- 90% round length attainment (interval between screening) of 36 months
- at least one direct digital mammography machine in place.

Guidance has also recommended that local screening services do not extend their programmes until the following NHSBSP best practice is maintained:

- screening to result within two weeks
- screening to assessment attainment of three weeks
- film readers reading a minimum of 5,000 screening mammograms every year
- technical recall/repeat rates of no more than 3%.

4.4.3 Tackling inequalities in breast screening

A number of inequality issues apply to breast screening. Although women aged over the invitation upper age (currently 70, but rising to 73 as the programme is extended) are entitled to free breast screening on request, they largely consider that they are no longer at risk. Commissioners may wish to consider improving the communication of the benefits of screening to women locally, together with mechanisms for increasing access (e.g. publicising the fact that women do not need to see their GP to request screening). It is also known that older women often delay presentation of breast cancer, and an improved awareness of the increased risk could cover both attendances at screening and early presentation of symptoms. Women from black and minority ethnic groups are also known to participate in screening at lower rates, as are women from the more deprived social groups. Local strategies should be developed to address these inequalities, according to the needs of the local population.

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Key commissioning questions for breast screening	Where to find the answers
Coverage/uptake	
What is the uptake of breast screening at first call (prevalent screen)?	Breast screening unit or Quality Assurance Reference Centre (QARC)
What is the uptake for subsequent routine invitations (1) in previous attenders (incident screens)? (2) in previous non-attenders?	 Breast screening unit or QARC (1) This should be very high (~90%), as previously screened women continue to attend (2) Likely to be only about 21% of those invited, indicating persistent inequalities
What is the coverage for breast screening? (Overall figure influenced by programme slippage) By GP practice? (Poor response in some practices indicates lack of practice support)	NHSBSP statistics for 2009/10 from National Statistics/ NHS Information Centre for whole PCT. www.ic.nhs.uk/statistics-and-data-collections/ screening/breast-screening/breast-screening- programme-england-2009-10
What is the current screening round length?	Breast screening unit or QARC (target 36 months)
Waits	
What is the time from screening to normal results?	Breast screening unit or QARC (target two weeks)
What is the time from screening to assessment?	Breast screening unit or QARC (target three weeks)

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Key commissioning questions for breast screening	Where to find the answers	
Outputs/outcomes		
What proportion of women is referred for assessment (1) after their initial screen? (2) after subsequent (incident) screens?	Breast screening unit or QARC	
What proportions of screen-detected cancers are (1) small invasive cancers <15mm? (2) ductal carcinoma in situ (DCIS)?	Breast screening unit or QARC	
If the breast screening centre is not at your local hospital, what proportion of screen-detected breast cancers is treated by your local multidisciplinary team?	Breast screening unit, local symptomatic service or QARC	
What proportion of women over 70 is requesting breast screening?	Breast screening unit	

4.5 Cervical screening

The national computerised call/recall system for cervical screening was introduced in 1988, the first such programme in the EU.

Cervical screening is *not* a test for cancer but for abnormalities which, if left undetected and untreated, *may* develop into cancer. Within the NHS Cervical Screening Programme in England, women aged 25–49 are invited for free cervical screening every three years, and women aged 50–64 every five years. Women over 64 are invited if their previous three tests were not clear or if they have never been screened.

In May 2004, IARC concluded that organised and quality controlled cervical screening can achieve an 80% reduction in the mortality of cervical cancer. In July 2004, Professor Julian Peto and colleagues published a paper in *The Lancet*, 'The cervical cancer epidemic

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that screening has prevented in the UK'.⁷ The paper concluded that cervical screening has prevented an epidemic that would have killed about one in 65 of all British women born since 1950 and culminated in about 6,000 deaths per year in this country. At least 80% of these deaths, up to 5,000 per year, are likely to be prevented by screening. This means that about 100,000 women will have been saved from premature death by the cervical screening programme by 2030.

4.5.1 Coverage

Coverage of cervical screening has fallen nationally in recent years, particularly among younger women. The Quality and Outcomes Framework provides a perverse incentive for GPs not to encourage harder-to-reach women to attend, since they are allowed to discount persistent non-attenders. Commissioners should pay particular attention to increasing coverage among women aged 25–35, which has been falling for the past 10 years. These women may particularly appreciate convenient and out-of-hours services, together with high quality and speedy communication materials.

4.5.2 Two week turnaround of results

The Operating Framework for the NHS in England 2011/12 states that commissioners should ensure that cervical screening results continue to be received within 14 days. As recommended by the Advisory Committee on Cervical Screening, the threshold for achieving this has been set at 98%. By taking a complete screening pathway approach, achieving a 14 day turnaround time has also been shown to be cost saving, with an average £100,000 saved per unit per year. Some cancer networks are using this in their local Quality, Innovation, Productivity and Prevention (QIPP) programmes.

4.5.3 Human papilloma virus (HPV) vaccination and the cervical cancer screening programme

HPVs are a group of over 100 viruses, some of which are sexually transmitted and are known to cause cervical cancer. In most people the virus is cleared naturally by the immune system, but it persists in some women, conferring a high risk of cervical cancer. Most women (and men) contract the sexually transmitted virus at some point in their lives. The most common high risk types for cervical cancer are types 16 and 18, with types 31 and 33 also being common. The prevalence of different types varies to some extent in different parts of the world. High risk HPV types have been found in 99% of cervical cancers.

HPV vaccination for girls aged 12–13 (school year 8) was introduced in September 2008. This is not expected to have an impact on the screening programme for a decade or more, but commissioners may wish to review the messages about HPVs and cervical cancer, bearing in mind that the girls' mothers will be in the eligible age range for cervical screening.

7 Peto J, Clare Gilham C, Olivia Fletcher O and Matthews FE (2004) The cervical cancer epidemic that screening has prevented in the UK. *The Lancet* 364(9430): 249–56.

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HPV testing as triage (sorting) for women with mild or borderline cervical screening test results has been piloted and shown to be effective. Women with mild or borderline results are tested for HPV and, if negative, are returned to the routine screening programme. Women who are HPV positive are referred for colposcopy. HPV testing can also be used to test whether women who have had cervical abnormalities treated have been cured, and this has been shown to be effective. As set out in IOSC, HPV testing as triage is being rolled out across England for women with mild or borderline cervical screening test results and as a test of cure for treated women. *The Operating Framework for the NHS in England 2011/12* states that commissioners should work with their local services and NHS Cancer Screening Programmes to implement HPV testing as triage for women with mild or borderline results, leading to a more patient centred service and major cost savings.

Key commissioning questions for cervical screening	Where to find the answers
Coverage/uptake	
What is the coverage of cervical screening of the target age group (25–64)? (<3.5 years and <5 years since last adequate test)	NHS Cervical Screening Programme statistics for 2009/10 from National Statistics/NHS Information Centre for whole PCT www.ic.nhs.uk/pubs/cervscreen0910
What is the coverage of cervical screening in women aged 25–35?	Primary care support service or QARC
What is the coverage of cervical screening by GP practice?	Primary care support service
What is the proportion of women aged 25–64 who have never been screened by GP practice?	Primary care support service

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Key commissioning questions for cervical screening	Where to find the answers
Waits	
What is the current turnaround time from taking of the cytology sample to the woman receiving her results?	Primary care support service or QARC
 What are the current waiting times for colposcopy clinics for (1) suspected invasive cancer or suspected glandular neoplasia? (2) high grade abnormalities (moderate/severe dyskaryosis)? (3) low grade abnormalities (borderline or mild dyskaryosis – most unlikely to be cancer but warrants referral to check)? 	Colposcopy clinic or QARC (Suspected invasive cancers and suspected glandular neoplasia should already be fast-tracked and seen within two weeks, and high grade abnormalities within one month)
Outputs/outcomes	
What proportion of women has (1) inadequate results? (2) abnormal results requiring referral to colposcopy?	Primary care support service or QARC
What proportion of invasive cervical cancers is diagnosed in women who have been screened in the last five years? How many have negative results?	Primary care support service or QARC

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4.6 Bowel cancer screening

Roll-out of the NHS Bowel Cancer Screening Programme began in 2006, and full roll-out across England was completed in July 2010. The programme is one of the first national bowel screening programmes in the world, and the first cancer screening programme in England to invite men as well as women.

Research undertaken in Nottingham (UK) and Funen (Denmark) in the 1980s showed that screening men and women aged 45–74 for bowel cancer using the faecal occult blood test (FOBt) could reduce the mortality rate from bowel cancer by 16% in those screened. An independently evaluated pilot in Warwickshire and Scotland showed that this research can be replicated in an NHS setting. Based on the final evaluation report of the pilot and a formal options appraisal, the programme in England is screening men and women aged 60–69.

Experts estimate that by 2025, around 2,400 lives could be saved every year by the NHS Bowel Cancer Screening Programme. Each year around 2 million men and women in their 60s are sent a self-sampling kit (the FOBt) to use in the privacy of their own homes. The kit is then returned by post to a regional laboratory (programme hub). Men and women are invited to participate every two years. The FOBt kit is used to examine stool samples to see if there is hidden blood, which is a sign of possible bowel cancer. If the test is positive, people are invited for a full bowel scope (a colonoscopy) in a local screening centre to check for bowel cancer. Five programme hubs across England are providing call/recall services, sending out the testing kits, interpreting the completed kits and sending out results. Some 58 local screening centres provide colonoscopy services for the 2% of men and women who have a positive FOBt result. Around 1 in 10 of those with a positive FOBt result will be found to have bowel cancer at colonoscopy. Around 4 in 10 will be found to have polyps called adenomas which, if left undetected and untreated, may have gone on to develop into cancer. Most polyps can be removed during the colonoscopy procedure.

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4.6.1 Extending screening to men and women aged 70–75

The NHS Bowel Cancer Screening Programme is currently being extended to men and women from age 70 to their 75th birthday. *The Operating Framework for the NHS in England 2011/12* states that the extensions begun in 2010/11 should continue and be maintained for 2011/12. Those centres whose original two-year screening round was due to end in 2011/12 should implement the extension on completion of the original round. Those whose original round is due to end beyond 2011/12 should prepare to expand on completion of the original round. Men and women aged over 75 will be able to self-refer for screening every two years if they wish.

4.6.2 Flexi sigmoidoscopy (FS)

FS is an alternative and complementary bowel screening methodology to FOBt. New evidence shows that men and women aged 55 attending a one-off FS screening test for bowel cancer can reduce their mortality from the disease by 43% (31% on a population basis) and reduce their incidence of bowel cancer by 33% (23% on a population basis). FS involves having a thin, bendy tube put a short way into the rectum and lower bowel. The doctor uses the scope to look at the inside wall of

the bowel and remove any small growths (polyps) that are there. Bowel cancers usually develop very slowly from adenomas. By removing them at an early stage it is possible to prevent bowel cancers from developing.

A randomised controlled trial funded by Cancer Research UK, the Medical Research Council and NHS R&D took place in 14 UK and six Italian centres, and evaluated screening for bowel cancer using a single FS between 55 and 64 years of age, removing small polyps by FS and providing colonoscopy for 'high risk' polyps. The study concluded that FS is a safe and practical test and, when offered only once between the ages of 55 and 64, confers a substantial and long lasting benefit. Based on the trial figures, experts estimate that the programme would prevent around 3,000 cancers every year and save thousands of lives.

IOSC set out how the DH has committed to invest £60 million between 2011 and 2014 to incorporate FS into the current bowel screening programme. Pilots will begin in 2011/12 with the aim of achieving 30% coverage by the end of 2013/14 and 60% by the end of 2014/15. It is envisaged that full roll-out will be achieved in 2016.

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Key commissioning questions for bowel cancer screening	Where to find the answers
Coverage/uptake	
What is the uptake for bowel screening in the invited population?	Bowel screening centre or programme hub
Waits	
 What proportion of those requiring referral (1) is seen at an assessment clinic within two weeks of the FOBt result? (2) has their colonoscopy within four weeks of the FOBt result? 	Bowel screening centre
Outputs/outcomes	
Do >85% accept colonoscopy after a positive FOBt?	Bowel screening centre
Do all screening colonoscopists meet national standards for workload and performance?	Bowel screening centre
Coverage/uptake	
What are the detection rates for (1) cancer? (2) adenomas?	Bowel screening centre

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Key commissioning questions for bowel cancer screening	Where to find the answers
What proportion of bowel cancers in the population invited for screening is screen-detected?	Colorectal multidisciplinary team data
 If the bowel screening programme has not yet started in your PCT: (1) What are the waiting times for endoscopy? (2) Has your proposed bowel screening centre been Joint Advisory Group-accredited? (3) Have at least two colonoscopists been accredited for bowel screening? (4) When is the proposed start date for screening? 	Local bowel screening steering group/proposed host trust for bowel screening centre/bowel screening lead

4.7 Best practice on commissioning all screening programmes

Commissioners will find that all national cancer screening guidance and standards are available on the NHS Cancer Screening Programmes website: www.cancerscreening.nhs.uk

4.8 Prostate Cancer Risk Management Programme

There is no national prostate cancer screening programme, but suitably informed individuals may be

tested through the Prostate Cancer Risk Management Programme (PCRMP). Commissioners should ensure that local GPs are aware of, and are utilising, the information provided by the PCRMP, which was re-launched in late summer 2009. They should also ensure that those local laboratories providing testing for the local population are using tests that conform to national standards and are applying the nationally recommended, evidence-based, age-related referral guidance. The PCRMP materials for use by primary care and individuals can be found at: www. cancerscreening.nhs.uk/prostate/informationpack.html

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4.9 Cancer Commissioning Toolkit metrics

The CCT contains the following related metrics. These can be found by accessing the corresponding section **Awareness, screening and early detection** and the sections **Screening** and **Referrals**, either via the dashboard or the contents page.

4.9.1 Screening

- Screening coverage
- Screening coverage, time trend.

4.9.2 Referral

- Two week wait performance
- Two week rule (TWR) performance trend by commissioners/networks
- TWR performance time series by PCT
- Percentage TWR with cancer diagnosis
- Number of TWR with cancer diagnosis
- Two week wait exhibited (non-cancer) breast symptoms performance.

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5. Assessment, diagnosis and staging

This chapter will be added to at a later date.

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6. Commissioning improved treatment services

6.1 Meeting waiting times

6.1.1 Key issues/background

The recent *Review of Cancer Waiting Times Standards*,¹ the findings of which were incorporated into the document Improving Outcomes: A Strategy for Cancer² (2011) confirmed that, overall, cancer waiting time standards should be retained.

Shorter waiting times can help to ease patient anxiety and, at best, can lead to earlier diagnosis, quicker treatment, a lower risk of complications, an enhanced patient experience and improved cancer outcomes. The current cancer waiting times standards have therefore been retained in *The Operating Framework for the NHS in England 2011/12*³ with the addition of the 31 day waiting time standard for subsequent radiotherapy treatment. Commissioners will need to continue to reflect this in the contracts that they agree with providers. The specific waiting times standards incorporated into the Operating Framework for 2011/12 either wholly or as part of an aggregate headline or supporting measure are:

- the two week wait from urgent GP referral for suspected cancer to first hospital assessment for all cancers
- the one month (31 day) wait from decision to treat to first definitive treatment
- the two month (62 day) wait from urgent GP referral for suspected cancer to first definitive treatment (Note: the pathway should be 31 days from urgent GP referral to first treatment where the suspected cancer is testicular cancer, acute leukaemia or a children's cancer)
- the two week wait for a symptomatic breast referral (where cancer is not suspected) to first hospital assessment
- the 31 day wait from decision to treat or the earliest clinically appropriate date to start of subsequent treatment where that treatment is surgery, an anti-cancer drug regimen or radiotherapy, for all cancer patients including those diagnosed with a recurrence

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1 www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123395.pdf

- 2 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371
- 3 www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122736.pdf



- the 62 day wait, from referral from an NHS Cancer Screening Programme (breast, cervical or bowel) to first definitive treatment
- the 62 day wait from a consultant's decision to upgrade the urgency of a patient (e.g. following a non-urgent referral) to first definitive treatment.

Concerted effort and co-ordination across primary, secondary and tertiary care have meant that these waiting time standards (with the 31 day wait from decision to treat or the earliest clinically appropriate date to start of subsequent radiotherapy treatment only being implemented from Q4 2010/11) have been met and sustained at a national level. However, variation continues at a localised provider level and it is important that commissioners investigate the implications for their patients.

This section focuses on ensuring that the cancer waits pathways are being delivered for patients in a sustainable manner.

6.1.2 Performance indicators

'Ready reckoners'

Data on all patients whose care is covered by the cancer waiting times standards is required to be uploaded onto the Cancer Waiting Times Database (CWT-Db); this is

4 www.isb.nhs.uk/documents/dscn/dscn2008/dataset/202008.pdf

mandated in Dataset Change Notice (DSCN) 20/2008.⁴ As a measure of data completeness commissioners might wish to be guided by 'ready reckoners', based on both incidence data provided by the cancer registries and expected throughput of cancer patients in their provider organisations. Suggestions for calculating local ready reckoners are:

- all cancer two week wait providers might be expected to make a quarterly submission of data that represents a minimum of 90% of the average quarter from the previous year
- the two week wait for breast symptoms (where cancer was not initially suspected) – providers might be expected to make a quarterly submission of data that represents a minimum of 90% of the average quarter since the standard was implemented from 1 January 2010
- all cancer 31 day wait for first definitive treatment providers might be expected to make a submission of data each quarter that is at least 90% of the average quarter from the previous year
- all cancer two month (62 day) wait for first definitive treatment – providers might be expected to make a submission of data each quarter that is at least 90% of the average quarter from the previous year

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- 31 day wait for subsequent radiotherapy commissioners might assume that there will be 190 new courses of teletherapy or chemoradiotherapy (both requiring beam radiation) per million population per month and that 82% of these will be subsequent treatments. Above this figure commissioners might wish to consider demand for other forms of radiotherapy (brachytherapy and proton therapy)
- 31 day wait from decision to treat or the earliest clinically appropriate date to start of subsequent treatment where that treatment is surgery or an anti-cancer drug regimen – providers might be expected to make a submission of data each quarter that is at least 90% of the average quarter from the previous year.

There are some assumptions in these models that local service patterns and reconfiguration may invalidate. However, ready reckoners constructed in this manner should be robust enough to support local performance management and service improvement works. It should be noted, however, that models of this type are not robust enough to support a complete audit, and so we would always recommend an audit against local systems, e.g. Patient Administration or Radiotherapy Verify & Record systems.

A robust central methodology has not yet been developed for the 62 day wait, from referral from an

NHS Cancer Screening Programme to first definitive treatment, though commissioners may wish to consider setting local ready reckoners based on published data regarding the levels of invasive cancer identified by NHS cancer screening services.

Operational standards

The cancer waiting time standards have helped to drive service improvement and have been beneficial for patients by ensuring that diagnosis and treatment happen in the shortest appropriate timescale and in reducing patient anxiety related to delays in being assessed, diagnosed with and treated for cancer. An aim for commissioners of these services should therefore be to ensure that as many patients as possible are seen and treated within the timescales defined by the cancer waiting times standards in the Operating Framework.

However, commissioners should consider that for a number of patients it is not possible or appropriate to treat them within the standard times. Within any given period there will be a number of patients who are not available for treatment because they elect to delay their treatment (patient choice) or are unfit for their treatment, or it would be clinically inappropriate to treat them within the standard time. Reasons for this vary according to individual patients and the type of cancer. For example, an inconclusive trans-rectal ultrasound biopsy for suspected prostate cancer will be repeated, but there will need to be a time delay before the patient

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To take into account the proportion of patients who will not be clinically able to be seen/treated within the cancer waits standard times or who will choose to wait longer than the standard time, operational standards, which specify the levels of achievement that are possible and therefore expected have been published,⁵ as shown below:

- 93% for the all cancer two week wait from urgent GP referral for suspected cancer to first hospital assessment
- 93% for the two week wait for a symptomatic breast referral (where cancer is not suspected) to first hospital assessment
- 96% for the one month (31 day) wait from decision to treat to first treatment
- 98% for the 31 day wait from decision to treat or earliest clinically appropriate date to start of subsequent anti-cancer drug regimens

- 94% for the 31 day wait from decision to treat or earliest clinically appropriate date to start of subsequent surgical treatments
- 94% for the 31 day wait from decision to treat or earliest clinically appropriate date to start of subsequent radiotherapy treatments
- 85% for the two month (62 day) wait from urgent GP referral for suspected cancer to first definitive treatment
- 90% for the 62 day standard from a referral from an NHS Cancer Screening Programme (breast, cervical and bowel) to first definitive treatment.

No national operational standard has yet been set for the 62 day standard from a consultant's decision to upgrade to first treatment.

Patients who are clinical exceptions, or who breach a waiting time standard for another legitimate reason such as choice, should continue to be recorded on the CWT-Db by providers as mandated in DSCN 20/2008 even though they breach their waiting times standard. All providers of cancer services are expected to achieve these predetermined operational standards.

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 $5 \quad www.dh.gov.uk/en/Publications and statistics/Letters and circulars/Dearcolleagueletters/DH_103436$

Adjustments to cancer waiting times Adjustments are when a trust can effectively 'stop the

clock' for a given period to take into account something along the cancer patient pathway that unavoidably extends the waiting time. There are two possible adjustments for cancer waiting times:

- during an outpatient wait a clock can be re-set if a patient does not attend their initial outpatient appointment as they have failed to engage with their NHS provider
- during a wait for inpatient (day case or ordinary admission) treatment – a pause will be possible where the patient declines a 'reasonable' offer of admitted treatment.

More detailed best practice on cancer waiting times is available on the NHS Connecting for Health website (nww.connectingforhealth.nhs.uk/nhais/cancerwaiting/ documentation). Commissioners and providers should note that the main behavioural guidance document *Cancer Waiting Times: A Guide*⁶ is kept under review and periodically updated.

6.1.3 Challenges to organisations

The key challenge to organisations in meeting the cancer waiting times standards is to identify and develop robust and effective clinical and information pathways for all patients within the scope of these standards to ensure that they are treated in a timely fashion with minimum opportunities for unnecessary delays that could impact on their experience of care or, in a worst case scenario, their outcome.

In many networks, this has required, and in some places still requires, service redesign both within and between organisations and across the pathway of care to ensure that the required waiting times can be delivered in a sustainable manner.

In terms of delivering the cancer waiting times standards, providers tend to fall into one of three categories:

• those delivering and sustaining the required level of service through robust, effective clinical and information pathways

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 ${\small 6} \quad nww.connecting for health.nhs.uk/nhais/cancerwaiting/cwtguide7.pdf$

- those achieving the standards through short-term, unsustainable methods (which can be very resource intensive and costly to commissioners, for example where waiting list initiatives are repeatedly used to clear backlogs when there is a capacity/demand imbalance)
- those struggling to achieve some or all of the cancer waiting times standards, which may be because of a lack of effective pathways.

Commissioners need to ensure that robust arrangements are in place, with:

- processes to identify and track patients along the waits pathways
- effective pathways this may require pathway redesign where necessary (e.g. considering how breast clinics are run) and also building up capacity in areas such as radiotherapy, incorporating, where appropriate, the Cancer High Impact Changes⁷ identified by NHS Improvement as being of benefit to patients
- prospective patient management and navigation systems in place – implementation of a local Priority Target List (PTL) should support the steering of patients through the system including within and across organisations

• local systems in place to capture data on where patients are in the pathway so that it is possible to track patients and demonstrate that the standards are being achieved.

Additionally, commissioners need to be able to performance manage provider organisations against these standards. This might require more detailed analysis of patient-level data if problems are identified in delivering particular standards as a whole or for particular tumour groups. These local 'insights' provide important quality indicators of the local service and enable organisations to monitor or audit all patients against local pathways. As a result, when a breach does occur, it is more apparent whether there is a local service issue that may need to be addressed, or if it has been a one-off departure from normal clinical practice. Examples of useful indicators are included within the commissioning questions in the following section.

Achieving and sustaining the cancer waiting times standards requires time, determination, focus and combined organisational effort, with strong clinical and managerial leadership. Further information on achieving and sustaining cancer waiting times can be found in the 'How to' guide and other supporting publications.⁸

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7 www.improvement.nhs.uk/cancer/documents/CSC_High_Impact.pdf

8 www.improvement.nhs.uk/Publications/tabid/56/Default.aspx

6.1.4 Commissioning questions

The key questions that commissioners should ask to assure themselves that they are commissioning appropriate clinical pathways, delivered in a timely manner and based on the cancer waits information, are:

1. Are organisations regularly achieving the operational standards for all the cancer waiting times standards?

If the answer is no, then organisations need to provide evidence of what they are doing to rectify the situation within an acceptable time. For example:

- use of a local PTL to prospectively track patients on these pathways and identify those who need to be prioritised for diagnostic tests, staging or treatment dates
- development of timed pathways (agreed by the local Cancer Network Tumour Site Specific Groups) – see www.cancerimprovement.nhs.uk

2. What percentage of all cancer patients are referred via urgent GP referral for suspected cancer?

Approximately 44%⁹ of all patients receiving first definitive treatment for cancer in the English NHS

entered secondary care via an urgent GP referral for suspected cancer in Q2 2010/11 and were therefore covered by the two week wait. This percentage may differ by cancer type but it is an indicator of how many patients are coming through this route and whether more can be done to educate the public and GPs about the signs and symptoms of cancer.

It is useful to review urgent referrals and conversion rates and compare with local and national levels (see below). Particular attention should be paid to low referrals and low conversion rates. External factors such as rates per population and age might need to be taken into account.

Organisations could be asked to provide evidence on all referral routes into their organisation, especially if there are other locally agreed services in operation to fasttrack patients into their services, e.g. straight to test processes.

3. What percentage of all urgent GP referrals for suspected cancer are diagnosed with cancer – for all cases, and by different cancer type?

It is estimated that 10%¹⁰ of all patients referred urgently for suspected cancer by their GP will be

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9 Q2 2010/11 Cancer Waiting Times Database

10 Q2 2010/11 Cancer Waiting Times Database

subsequently diagnosed with primary cancer; although this proportion will differ by tumour, it can be used to give an indication of the volume/accuracy/ appropriateness of referrals from primary care.

- If the benchmarked data shows that an organisation's population falls within the bottom quartile (fewer patients subsequently diagnosed with cancer than in most other organisations), then questions may need to be asked about the interpretation of the NICE referral guidelines for suspected cancer.
- In addition, local teams in secondary care could be asked via local contract variation to audit urgent GP referrals received and to regularly feed back on their findings to commissioners or cancer networks supporting commissioners.

GPs should use their clinical judgement to determine what to tell a patient and when but it is deemed good practice for a GP to ensure that a patient understands that they need to be referred urgently and for what reason where possible (as recommended in NICE referral guidelines for suspected cancer – see http://guidance. nice.org.uk/CG27). If the NICE guidelines are followed, it will hopefully encourage patients to accept the earliest appointment where possible. It would also be helpful for a GP to reiterate the importance of keeping an appointment once it has been made. Detailed information covering uptake/referral rates and the numbers of patients subsequently diagnosed with cancer has been incorporated into GP practice profiles to support better localised commissioning.

4. What is the median time period (days) between the two week referral and date of decision to treat for different cancer types?

The time period between referral and the agreement of a treatment plan gives an indication of any potential bottlenecks in the diagnostic phase of the pathway.*

(Information associated with questions 1 to 5 is benchmarked within the Cancer Commissioning Toolkit (CCT), with the exception of the item marked *.)

5. What percentage of 62 day patients within the cancer network are 'seen and treated' within more than one organisation (known as an inter-provider transfer) and are treated within the 62 day period, and is this increasing over time?

This is an indicator of patients whose pathways are managed by multiple providers of care and if/how that might impact on the speed with which their diagnosis is achieved and treatment delivered.

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Print this page Print this section 8/56 If the performance for this metric is substantially below 85%, all organisations should demonstrate their commitment to unified, robust pathways across organisations, and provide, on a quarterly basis, a breach analysis to demonstrate where the delays in service are.

In addition, the cancer network and all local organisations should provide evidence of local communication and information-sharing protocols, with evidence that there is synergy with the clinically effective pathway.

6. Overarching questions commissioners should ask include:

- a Do you commission effective, timed tumour or symptom-specific pathways for all patients with suspected or confirmed cancer within and across organisations?
- b Do you have robust, specific patient information and administrative systems, which support effective pathway management?
- c How confident are you that the organisations you commission services from can deliver/are delivering all the cancer waiting times standards and that delivery is sustainable?
- d Is your organisation making effective use of cancer network service improvement resources to support delivery?
- e Is your cancer network effective in supporting sustainable waiting times for cancer patients?

7. In addition, commissioners should ensure that the following actions take place to support and sustain delivery. They should:

- a Develop (if this has not already happened) and implement a strategic framework for cancer waits delivery in conjunction with the SHA.
- b Nominate an executive commissioning cancer lead and ensure active and senior membership of the Cancer Network Board.
- c Commission effective redesigned tumour or symptom-specific pathways for all patients with suspected or diagnosed cancer within and across organisational boundaries which are incorporated into the commissioning quality specifications with trusts (additional information and best practice on commissioning can be obtained through the Cancer Commissioning Toolkit).
- d Use local service improvement teams to support pathway redesign within primary care and across the primary/secondary care interface.
- e Agree referral best practice and audit compliance, ensuring that systems and processes are developed to include a feedback loop to primary care.
- f Ensure that there is adequate diagnostic capacity and provision to meet the waiting times standards.
- g Implement robust and effective information systems that provide good information for management decisions, as alluded to in the national contract for acute services.

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- h Monitor network effectiveness in supporting delivery.
- i Contribute effectively to the network's work programme including supporting network-wide pathways and inter-trust transfer processes.
- j Ensure that networks are fit for purpose and are held to account for delivering agreed objectives through formal review.

6.2 Tumour key questions – high quality surgical and other services in line with Improving Outcomes guidance

Comprehensive service guidance for cancer has been published by the DH and (since 2002) by NICE. Some of this guidance requires the reconfiguration of surgical oncology; all of it requires a team approach to patient care. The Improving Outcomes guidance (IOGs) is mandated by the *NHS Cancer Plan* and reinforced by the *Cancer Reform Strategy. The Operating Framework for the NHS in England 2011/12* requires commissioners to work with their cancer networks on implementation of those services that are not yet IOG compliant. Implementation of the guidance is audited through the cancer peer review process, the reports of which are published.

The principle behind reconfiguring specialist surgical oncology is founded on two tenets. First, there is a solid evidence base of a positive relationship between volume (of surgery performed) and outcome; second, the need for specialists to be assembled into teams in order to offer a sustainable and continuous specialist service. The consequence is that specialist cancer surgery should only be performed by specialists working in teams that are located in approved hospitals serving a particular population size.

There are a number of generic metrics that apply to all cancer multidisciplinary teams, and these are listed below, together with the source of the data. Some of these metrics are not pertinent to all tumour sites – for example, for breast and colon cancers, it is less relevant to look at inter-hospital breaches, as this surgery does not usually require referral to a specialist centre. In addition, each of the tumour sites has tumour-specific issues to address, and these are identified in the individual tumour sections.

Improving intervention rates for older patients, highlighted in Improving Outcomes: A Strategy for Cancer,¹¹ should also direct commissioners to ensure that they are provided with data about regional variations in intervention rates for older people. This will focus attention on improving cancer survival and mortality rates and improve patient experience.

In recent research it was shown that approximately 23% of cancer patients were first diagnosed via an emergency route. Emergency presentation is strongly associated with poorer survival Improving Outcomes: A Strategy for Cancer. It is important that this is reviewed for all

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6.2.1 Cancer multidisciplinary teams (MDTs)

Where they have been agreed we have used metrics/ outcomes developed by the NCIN Site Specific Reference Groups and Cancer Peer Review in their Clinical Lines of Enquiry. The first section provides generic key questions that commissioners may wish to use to assess their provider organisations and the next sections relate to individual tumours.

Generic key commissioning questions for cancer MDTs	Where to find the answers
Team working	
Does each specialist team dealing with a particular type of cancer have the relevant core membership?	Cancer Quality Improvement Network System (CQuINS) Annual peer review report (www.cquins.nhs.uk/?menu=info)
How good is attendance at MDT meetings for each team? (Should be at least two-thirds.) How good is cover for team members?	CQuINS
What is the overall level of compliance with peer review measures for each team dealing with a particular type of cancer?	CQuINS
How many new cancers does each team deal with in a year?	Cancer Waiting Times Database (CWT-Db)
What proportion of new cancer patients is discussed at MDT meetings?	Local audit

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Generic key commissioning questions for cancer MDTs	Where to find the answers
Waiting times/access	
What proportion of cancers are diagnosed via an emergency presentation by tumour site, compared with national figures?	Local audit
What proportion of new cancers is referred through the urgent (2WW) route (and non-urgent route) and how does this compare with national figures?	CWT-Db
What proportion of 2WW referrals has cancer?	CWT-Db
Are the 31/62 day standards met for a particular type of cancer?	CWT-Db
Are there inter-provider transfer breaches?	CWT-Db
Is there streamlined access to assessment for co-morbidities?	Local information
Treatment	
What percentage of patients is entered into clinical trials?	Local information

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Generic key commissioning questions for cancer MDTs	Where to find the answers	
Length of hospital stay		
What is the average length of stay for a particular type of cancer?	Hospital Episode Statistics (HES)	
What is the average length of stay for a particular procedure?	HES	
What are the pre/post-operative bed days?	HES	
How many/what proportion of cases are readmitted owing to complications during a year?	HES	
Incidence/mortality/survival		
What is the incidence of a particular type of cancer in this locality?	Cancer Information Service (CIS)	
Is the age standardised mortality rate for a particular type of cancer falling in line with England/Europe?	CIS	
What is the 30 day mortality rate following surgery in this unit (e.g. relevant to oesophagus, gastric, pancreatic and lung cancer)?	Link to HES/registry	
What is the hospital mortality after resection?	HES	
What are the one-, two- and five-year survival rates?	CIS	
What proportion of all deaths is in hospital?	HES/Office for National Statistics (ONS)	

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Generic key commissioning questions for cancer MDTs	Where to find the answers
Audit	
Is staging and co-morbidity data collected on all new patients with cancer?	Local information
Does the unit participate in national audits?	National Clinical Audit Support Programme (NCASP)/ Breast Cancer Clinical Outcome Measures (BCCOM)
What proportion of cases is reported and with what level of data completeness for treatment and care-mix fields?	NCASP/BCCOM/local provider
Does the MDT/Network Site Specific Group collect (for the whole team and for individual surgeons) audit information on the number of operations performed and serious operative complications? Does the team have a process for review of complications?	Local information
Quality of patient experience	
What percentage is compliant with patient experience measures?	CQuINS
How well does your service compare with other trusts that offer the service?	National Cancer Patient Experience Survey 2010 www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsStatistics/DH_122516

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6.2.2 Breast cancer

Breast cancer surgeons should, for small lesions, offer the choice of mastectomy or breast conserving surgery (BCS), the latter normally with adjuvant radiotherapy. BCS should increasingly be offered on a short-stay (day case) basis, and is facilitated by using sentinel node biopsy to identify the minority of cases that require more extensive surgery to remove lymph nodes. Major breast surgery (excluding reconstruction) can be delivered in a day case or one night stay pathway. The Breast pathway is recommended by NHS Evidence and endorsed by the British Association of Day Surgery – there is also a best practice tariff in place. With regard to breast cancer choice and efficiency, women with small single tumours should be offered the choice of mastectomy, immediate breast reconstruction, or BCS with adjuvant non-surgical treatment if indicated. Minimally invasive surgery with early rehabilitation is desirable where possible.

The following are suggested breast cancer specific issues that could be addressed by commissioners in addition to the generic key commissioning questions, when looking for a high quality service.

Key commissioning questions for breast cancer	Where to find the answers	
Team working		
Does the breast cancer MDT treating your patients manage at least 100 diagnoses a year?	HES/local audit	
Does each surgeon manage at least 30 new cases a year?	HES/local audit	
Waiting times/access		
What proportion of newly diagnosed cases is not referred through screening or the two week referral route? (Should be less than 30% and aim for no more than 10%.) (Note that this will change with new target.)	Screening/CWT/local provider	

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Key commissioning questions for breast cancer	Where to find the answers
Treatment	
What is the ratio of mastectomy to BCS (the national average is close to 1:1)?	HES
What proportion of women receiving surgery for breast cancer has a sentinel node biopsy?	Local provider
What proportion of women receiving surgery for breast cancer has an axillary node clearance?	HES
What is the percentage of women offered access to immediate reconstruction surgery by the MDT or by referral on to another team and rate of uptake?	HES
What proportion of women undergoing resectional surgery and receiving adjuvant or neo-adjuvant chemotherapy is tested for HER2 prior to commencement of drug treatment?	Local provider
Length of hospital stay	
What is the average length of stay for breast cancer with any surgical procedure? (This will provide an overall average, including reconstruction.)	HES
What proportion of women undergoing BCS is treated as day cases or has a length of stay of two days or less? (This should become the norm.)	HES

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Key commissioning questions for breast cancer	Where to find the answers
What is the average length of stay for BCS?	HES
What proportion of patients undergoes mastectomy using the one night pathway?	HES
Audit	
Does the team submit data to the BCCOM dataset (managed by the West Midlands Cancer Intelligence Unit)?	BCCOM

6.2.3 Lung cancer

Lung cancer remains an area of concern, since the overall survival rate has improved little over the past decade and there continue to be large variations in practice around the country. In particular, resection rates aimed at cure vary from less than 5% to around 20%, and access to chemotherapy and Continuous Hyperfractionated Accelerated Radio Therapy (CHART) is also highly variable.

The proportion of patients for whom the diagnosis is confirmed by histology or cytology is well over 80% in some centres and nearer 50% in others. This histological confirmation rate is probably a good surrogate marker of the overall standard of a lung cancer service, and is more easily measured than many other indicators. Although the five-year survival rate remains very low (6–8% in this country compared with 15–17% in some other European countries), good quality survival can be extended with appropriate treatment, including chemotherapy, radiotherapy and possibly photodynamic therapy. Longer-term survival is normally achieved with surgery, radical radiotherapy or combination chemoradiation in patients with non-small cell lung cancer (NSCLC). Virtually all patients with NSCLC in whom surgery, radical radiotherapy or combination chemoradiation is planned should be staged with Positron Emission Tomography/Computerised (Axial) Tomography (PET/CT) prior to treatment.

The less common small cell lung cancers (SCLC) generally respond well to chemotherapy, but five-year survival is only around 2%, and most such patients

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Print this page Print this section 17/56 are not suitable for surgical resection. However, even with this highly chemo-sensitive tumour, only 58% of patients nationally receive chemotherapy, with rates varying from under 50% to over 80%.

The National Lung Cancer Audit (LUCADA) is now well established and is the source of much of the data quoted above. Data completeness and participation, however, are still limited in some areas. The following are lung cancer specific suggested issues that could be addressed by commissioners, in addition to the generic key questions, when looking for a high quality service.

Key commissioning questions for lung cancer	Where to find the answers
Prevention	
Is a smoking-cessation programme in place locally?	Commissioner
Treatment	
In what proportion of patients managed by the MDT is the diagnosis confirmed by histology or cytology?	Cancer registry
What is the curative surgical resection rate for patients with NSCLC?	HES/Cancer registry
What proportion of patients with NSCLC receives any form of active anti- cancer treatment (including surgery, chemotherapy and radiotherapy)?	Local provider/LUCADA
What proportion of patients with SCLC receives chemotherapy?	Local provider/LUCADA
Audit	
Does the team submit data to LUCADA?	Local provider/LUCADA

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6.2.4 Colorectal cancer

The operating framework for 2011/12 highlights the importance of giving GPs better access to flexi sigmoidoscopy/colonoscopy to improve earlier diagnosis of colorectal cancer.

Approximately 75–80% of patients presenting symptomatically with colorectal cancer will have a surgical resection aimed at cure. There have been improvements in the surgical management of rectal cancer in terms of outcome, as well as a reduction in the abdomino-perineal resection rate with permanent colostomy. Shorter lengths of stay and improved patient experience can be achieved by performing the surgery laparoscopically and by introducing enhanced recovery programmes. Trusts implementing this report achieving median lengths of stay of 5–6 days.

There has also been a large increase in the number of patients with liver metastases undergoing resection of the affected part of the liver – a procedure with reported five-year survival rates of as high as 45%. However, again there are large variations in practice.

Approximately 25% of patients with colorectal cancer present as surgical emergencies – mostly with obstruction, some with perforation. Recent evidence shows that emergency presentation is

strongly associated with poorer survival (see Improving Outcomes: A Strategy for Cancer¹²) and it is therefore more important that specialists should treat them. Paradoxically, this is less likely to happen. Recent best practice documents suggest new approaches to the management of emergencies, so that patients are transferred to specialist teams before surgery, especially in the case of obstruction. Emergency presentations with rectal cancer are less common and are usually due to haemorrhage. Such cases should only be operated on by designated rectal cancer surgeons.

Colorectal cancer is a common disease, which classically benefits from multi-modality treatment. Many patients with rectal cancer would receive, for example, preoperative radiotherapy, surgery from designated and specially trained surgeons and then chemotherapy (depending on the anatomical stage of disease). Developments in the quality of care and rehabilitation are altering patients' experience and outcomes significantly. It is consequently of major importance that the teams treating colorectal cancer patients have sufficient workload and experience to sustain their expertise.

The following are suggested colorectal cancer specific issues that could be addressed by commissioners, in addition to the generic key questions, when looking for a high quality service.

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Key commissioning questions for colorectal cancer	Where to find the answers	
GP access to diagnostics		
What is GP usage of flexi sigmoidoscopy/colonoscopy?	Local diagnostics providers	
Team working		
Does the team treating your patients manage at least 60 new patients each year?	HES	
Does each surgeon managing colorectal cancer (excluding emergencies) perform at least 20 curative resections each year?	HES	
Is there expertise within the team to offer minimally invasive (laparoscopic) bowel surgery to patients?	HES	
Access		
What proportion of patients with rectal cancer who are undergoing curative surgery receives pre- or post-operative radiotherapy?	Local provider	
Treatment		
What proportion of rectal cancer procedures is abdomino-perineal resections and is this high compared with other providers?	HES	
In what proportion of patients undergoing curative surgery is there leakage at the anastomosis?	Local provider	
In what proportion of patients undergoing curative resection is the circumferential resection margin free of tumour?	Local provider/National Bowel Cancer Audit (NBOCAP)	
What proportion of patients with a diagnosis of colorectal cancer has undergone surgery for the resection of liver metastases? (There is no standard rate but a population-based rate of 50–75 per million is achieved in the best centres.)	HES/local provider	

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Key commissioning questions for colorectal cancer	Where to find the answers
How many elective colorectal resections are undertaken laparoscopically in your local provider (nationally 33% are undertaken laparoscopically)?	HES
Does the hospital have an enhanced recovery programme in place?	Local provider
Length of hospital stay, readmissions and returns to theatre	
What is the average length of stay for patients with colorectal cancer with a surgical procedure? What is the pre- and post-operative stay? What is the level of readmissions and returns to theatre?	HES/local data
Audit	
Does the unit managing your patients submit complete data to the NBOCAP?	The 2009 and 2010 (shortly available) NBOCAP reports give case ascertainment and data completeness
What is 30 day post-operative mortality?	This data was recently published on www.ncin.org.uk. Trust CEOs and trust medical directors were sent this data in February 2011.
Compliance with Royal College of Pathologists minimum dataset?	Local data
What is the proportion of newly diagnosed colorectal cancers being staged with CT (and in the case of a rectal cancer, an MRI of the pelvis)?	Local data/NBOCAP

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6.2.5 Gynaecological cancers

The Improving Outcomes in Gynaecological Cancers guidance¹³ was published in 1999 and led to the centralising of treatment planning and most of the cancer surgery at a network level (with an assumption of 800,000 to 1 million population, this allows up to two specialist teams in the largest networks). The implementation of this guidance should now be complete. There is, however, some evidence that local teams are continuing to operate on a wider range of cancers than is approved in the guidance. Locally delivered surgery – which must first be approved by a specialist team – should be restricted to very early stage cancers of the uterus, and should amount to no more than 15–20% of the total of gynaecological cancer resections. The guidance covers cancers of the body of the uterus (endometrium), the uterine neck (cervix) and ovary, and rarer cancers of the vulva and vagina. Malignant germ cell tumours affecting children and young people should be managed in conjunction with specialist children's and young people's gynaecology teams.

Ovarian cancer is a difficult disease to treat and has a rather poor prognosis. Exemplary surgery and active non-surgical management should be expected. The following are suggested issues that could be addressed by commissioners when looking for a high quality service and are based on the Clinical Lines of Enquiry that have recently been developed by peer review and the NCIN Site Specific Gynaecological Group.

Key commissioning questions for gynaecological cancers	Where to find the answers
Team working	
What is the percentage of gynaecological oncology surgery performed outside a specialist team centre? (A figure of over 20% suggests that not enough of the surgery has been centralised.)	HES
Does every surgeon in the specialist MDT who manages gynaecological cancer spend at least 50% of their direct clinical care time on the management of cancer cases?	Local provider

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Key commissioning questions for gynaecological cancers	Where to find the answers	
Does every gynaecological oncologist performing ovarian cancer surgery perform in excess of 15 cases per year?	Local provider	
Treatment		
Can your ovarian cancer service demonstrate that there are systems in place to ensure that cases of suspected ovarian cancer are discussed by the MDT with review of imaging, +/- pathology and tumour markers to plan management, prior to the patient undergoing primary surgery?	Local provider	
What is the proportion of ovarian cancer cases that undergo surgery prior to the MDT review by the specialist MDT?	Local provider	
Does the hospital gynaecology team have an enhanced recovery programme in place?	Local provider	
Length of hospital stay		
What is the average length of stay for major gynaecological oncology surgical resections?	HES	
What percentage of endometrial cancer surgery is undertaken laparoscopically?	HES/local provider	
Can your service demonstrate that adequate resources exist to enable cancer nurse specialists to be present at key stages of the patient pathway?	Local provider	

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Key commissioning questions for gynaecological cancers	Where to find the answers
Audit	
Can the service demonstrate that processes are in place to ensure that core data items in the Royal College of Pathologists cancer dataset are included for histopathology reporting of endometrial carcinomas in hysterectomy specimens?	Local provider
Are systems in place to accurately assign and document the FIGO stage of every new case of gynaecological malignancy (plus nodal status where appropriate for cervical cancer), and report the stage distribution of cancers annually to the local cancer registry?	Local provider

6.2.6 Oesophago-gastric cancers

The original *Improving Outcomes in Upper Gastrointestinal Cancers* guidance,¹⁴ published in 2001, estimated that a population of 1 million would generate 250 incident cases of oesophago-gastric cancers and 100 radical resections per year. As a result of MDT working with improvements in staging and treatment options, the number of resections has reduced to 60–70 per million. A much higher resection rate would cast doubt on the effectiveness of staging and case selection. Specialist teams in approved specialist centres should perform all oesophago-gastric surgery.

Upper gastrointestinal (GI) cancers have a poor prognosis. Radical surgery, especially for oesophageal

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cancer, is disabling and has a significant operative mortality rate which is equivalent to other major surgery such as cardiac surgery, and should not be considered unless there is a chance of cure. All patients should be fully staged with multi-slice CT scanning; those undergoing radical treatment with oesophageal and oesophago-gastric junctional cancers should have an endoscopic ultrasound (EUS). Laparoscopy should be considered for all with oesophago-gastric junctional and gastric cancers and those considered for oesophageal surgery should be further staged with PET/CT.

The following are suggested issues that could be addressed by commissioners when looking for a high quality service.

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Key commissioning questions for upper GI cancers	Where to find the answers	
Team working		
Is any curative resection performed outside a specialist team centre? (There should be none.)	HES	
Waiting times/access		
How many patients are not seen within the 31 and 62 day waiting times targets?	CWT/local provider	
Treatment		
What are the curative resection rates for gastric and oesophageal cancers? (Overall rates should be about 20–25% for oesophageal and gastric cancer.)	HES – need total number of cases reviewed by MDT as denominator for both local and specialist service	
What proportion of patients undergoes pre-operative chemotherapy?	Local provider	
What is the average number of lymph nodes removed at radical surgery? What is the frequency of resection line involvement? What is the anastomotic leak rate? What percentage of patients returns to theatre?	Local provider	
Length of hospital stay		
What is the average length of stay for patients with oesophago-gastric cancer undergoing radical resection?	HES	
Audit		
Does the team submit data to the Association of Upper Gastrointestinal Surgeons (AUGIS) for national audit purposes, e.g. the National Oesophago-Gastric Cancer Audit (NOGCA)?	Local records	

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6.2.7 Pancreatic cancer

Pancreatic cancer is difficult to treat. Radiotherapy has little place and the benefits of chemotherapy are relatively modest, although adjuvant chemotherapy (with resectional surgery) is now well established and offers similar benefits to those in oesophago-gastric cancer.

Most patients present when the disease is beyond cure. Palliative care is central to managing these patients. Surgical resection is possible in a minority of cases, but careful staging is required, with three-dimensional imaging, endoscopic ultrasound and staging laparoscopy to avoid fruitless surgery.

The following are suggested issues that could be addressed by commissioners when looking for a high quality service.

Key commissioning questions for pancreatic cancer	Where to find the answers	
Team working		
Are any pancreatic resections performed outside designated specialist pancreatic cancer teams? (There should be none.) What proportion of patients is discussed at a specialist MDT?	HES	
Waiting times/access		
How many patients are not seen within the 31 and 62 day waiting times targets?	Cancer Working Times Database (CWT-Db)/local provider	
Treatment		
What is the curative resection rate for pancreatic cancer? (A rate above 15% is likely to imply inadequate assessment and staging, but there do appear to be higher rates in some specialist units.) What is the open and close rate (as an indicator of case selection for surgery)? What is the percentage of post-operative chemotherapy? What proportion of patients with jaundice is stented before surgery? What is the anastomotic leak rate (should be <10%)?	HES	

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Key commissioning questions for pancreatic cancer	Where to find the answers
Length of hospital stay	
What is the average length of stay for patients undergoing radical surgical resection?	HES
Audit	
Does the team submit data to the AUGIS hepato-pancreato-biliary (HPB) cancer resection database?	AUGIS

6.2.8 Urological cancers

NICE guidance on Improving Outcomes in Urological Cancers¹⁵ was published in 2002. It established several different levels of cancer teams. Local urology teams would still manage most patients with bladder, prostate and renal cancers. Specialist teams serving at least 1 million people would provide specialist surgical and radiotherapy treatments for people with localised prostate cancer who opt for radical treatment, for bladder cancers requiring radical surgery, and for a small number of renal cancers requiring complex surgical techniques. Designated specialist teams must undertake a minimum of 50 radical procedures (cystectomy and/ or prostatectomy) at an approved hospital site where surgery is undertaken. Testicular cancer should only be treated by teams serving at least a 2 million catchment population; and penile cancer by teams serving at least 4 million people. Implementation of this guidance should have been completed by the end of 2007.

recent years, owing to increased case ascertainment using blood tests for prostate-specific antigen (PSA) and biopsy. Although more than 10,000 men die of prostate cancer each year, it is not known how many cases are indolent or incidental findings which would not have required active treatment.

Prostate cancer is now the most common cancer in

men. The recorded incidence has increased rapidly in

Because access to PSA testing varies across the country, there is no consistency about the nature or importance of the disease. Where PSA testing rates are high, fiveyear survival rates will also tend to be high. However, these areas typically have mortality rates that are close to the national average. Conventional survival data is a poor guide to the quality of treatment services. To add to the uncertainty, men with localised prostate cancer (about 65% of all presenting cases) have several treatment options, whose relative value is uncertain.

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These include surgery (using open technique or laparoscope, with or without robotic assistance – robotic surgery reducing the length of stay), radiotherapy (conformal external beam or brachytherapy) or a more conservative approach of active surveillance, where treatment is postponed until there is evidence of active disease. The choice is essentially that of the man concerned (with some exceptions covered in the recent NICE clinical guidelines¹⁶). Radical prostatectomy is a complex operation and is uncommonly offered to men aged over 70 years. Radiotherapy is still the most common radical treatment used in prostate cancer. Some other treatments, such as cryosurgery or high-intensity focused ultrasound (HIFU), are not recommended, except in research settings.

Radiotherapy regimes vary across the country, with some centres, especially in the North of England, using 20

fractions, whereas the recommended regime involves at least 37 fractions. Also, some areas of the country have restricted access to brachytherapy, which is now the subject of Department of Health best practice.

All radical treatments for prostate cancer can have severe side effects, and the option of avoiding such treatment is preferred by many men. The management of more advanced disease is also contentious. Hormone therapy, using drugs, and orchidectomy are effective in slowing the progression of active disease but are also accompanied by serious unwanted effects. Chemotherapy is also emerging as a treatment option in the later stages of the disease.

The following are suggested issues that could be addressed by commissioners when looking for a high quality service.

Key commissioning questions for prostate cancer	Where to find the answers
Team working	
Are any radical prostatectomies performed outside a specialist team centre? (There should be none.)	HES

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		The challenge
Key commissioning questions for prostate cancer	Where to find the answers	Prevention
Treatment		Farlier diagnosis
What is the number of radical prostatectomies performed for prostate cancer, compared with the number receiving external beam radical radiotherapy, brachytherapy, other surgical treatments (e.g. HIFU, cryosurgery) and active surveillance as the first definitive treatment for early prostate cancer? (A reasonably even distribution between surgery, radiotherapy (any type) and active surveillance would be expected.) <i>Note: For cancer waits, active monitoring is where a diagnosis has been reached but it is not appropriate to give any active treatment at that point in time, but an active treatment is still intended/may be required at a future date. The patient is therefore monitored until a point in time when they are fit to receive, or it is appropriate to give, an active treatment. A patient</i>	Local provider	Assessment Treatment services • Waiting times • Tumour key questions • Radiotherapy • Systemic therapy • Toolkit metrics
a period of time rather than receive alternative treatment. It is not to be used for thinking time. For example, if a prostate patient is offered a range		Living with cancer
of treatments and wants to take a couple of weeks to think about the options, this is not active monitoring. However, if a prostate patient has		End of life care
that they do not want to pursue active treatment immediately but have		The future
the cancer kept under check by repeat PSA etc, this would be active monitoring. While a patient is being actively monitored they may receive symptomatic support.		Funding services
How many fractions are used in your radical radiotherapy regime? (Should be at least 37.)	Local provider	Print this page
Are conformal delivery and access to brachytherapy available?	Local provider	Print this section

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Key commissioning questions for prostate cancer	Where to find the answers
Length of stay in hospital	
What is the median length of stay for men undergoing radical prostatectomy?	HES
Are enhanced recovery programmes established in providers offering radical prostatectomy?	Local provider
Audit	
Is a clinical audit dataset recorded for prostate surgery? A minimum dataset should be an absolute prerequisite for commissioning. This should include audited records of pre-operative PSA, pathological stage/ grade, pre- and post-operative International Index of Erectile Function (IIEF) and International Prostate Symptom Score (IPSS) urinary symptom scores, length of stay, margin positivity rates, PSAs at three and six months, the relative rate of post-surgical radiotherapy to the prostate bed and the rate of artificial sphincter insertion within two years of surgery.	Local provider

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Key commissioning questions for prostate cancer	Where to find the answers
Is there a clinical audit dataset recorded for prostate radiotherapy? Measurements might include: • mean nadir PSA stage for stage at one year • rates of PSA failure (American Society for Radiation Oncology (ASTRO) definition of an increase of 2ng/ml above nadir) • potency rates at 12 months • referral rates to surgeons/physicians for urinary and bowel toxicity • use of neo-adjuvant hormone therapy for cT3 disease • use and duration of adjuvant hormone therapy for cT3 disease. For advanced disease: • proportion of patients receiving chemotherapy for palliation • number of palliative surgical interventions (nephrostomy/trans- urethral resection (TUR) channel).	Local provider
Treatment	
What is the provision of Bacillus Calmette-Guérin (BCG) \pm maintenance as a percentage of the presenting patients within year 1?	Local provider
Key commissioning questions for invasive bladder cancer	Where to find the answers
Team working	
Are any radical cystectomies performed outside a specialist team centre? (There should be none.)	HES

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Key commissioning questions for invasive bladder cancer	Where to find the answers
Treatment	
What is the cystectomy rate?	HES
What is the number of neobladder reconstructions? (Procedure should be available and, when offered, be taken up by at least 20%.)	HES/local information
What is the use of pelvic node dissection? (A bit more difficult to measure and quantify.)	Local provider
Length of hospital stay	
What is the length of post-operative stay?	HES
Are enhanced recovery programmes established in providers offering cystectomy?	HES
	1
Key commissioning questions for renal cancer	Where to find the answers
Treatment	
What is the proportion of nephron-sparing procedures for T1a disease? (Should now be most cases.)	Local provider
What is the recurrence rate/re-operation rate for nephron sparing? (Should be no more than 2%.)	Local provider

Treatment	
What is the proportion of nephron-sparing procedures for T1a disease? (Should now be most cases.)	Local provider
What is the recurrence rate/re-operation rate for nephron sparing? (Should be no more than 2%.)	Local provider
What is the ratio of laparoscopic vs. open nephrectomy for T1b and T2 disease? (The majority should now be done laparoscopically.)	Local provider
What is the percentage of advanced cases having debulking surgery and immuno/targeted therapy?	Local provider

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Key commissioning questions for renal cancer	Where to find the answers
What is the number of cases performed involving renal vein/inferior vena cava (IVC)? (Should not be carried out outside a designated and functioning specialist urological cancer team.)	Local provider
Length of hospital stay	
What is the length of post-operative stay?	HES
Incidence/mortality and survival	
What is the 30-day mortality? (Should be <2%.)	Cancer registry

Key commissioning questions for penile cancer	Where to find the answers
Treatment	
Are all cases discussed and treatment plans agreed by a designated supra-network penile cancer team? (Men undergoing reconstruction and/or lymph node dissection must be operated on at the host hospital of the supra-network penile cancer team; no penile cancer cases should be treated by local urology cancer teams, apart from biopsies.)	Local provider
Treatment	
What is the proportion of patients undergoing partial amputation or or organ preservation (glansectomy or radiotherapy) for T1 disease?	Local provider
What is the inguinal lymph node dissection rate for T2+/G3 disease?	Local provider

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Key commissioning questions for testicular cancer	Where to find the answers
Waiting times	
What is the time from diagnostic primary surgery to first consultation with a supra-network testicular cancer team?	CWT-Db
Treatment	
What percentage of cases with stage 1 non-seminomatous disease is given adjuvant chemotherapy?	Local provider
What percentage of cases with stage 1 seminoma is offered adjuvant radiotherapy/low dose chemotherapy/active surveillance?	Local provider
What percentage of cases is undergoing retroperitoneal lymph node dissection for residual masses? (Should be one in five of men with stage 2+ disease.)	Local provider
What percentage of cases requires/receives salvage chemotherapy?	Local provider
What is the mortality rate?	CIS

6.2.9 Head and neck cancers

The original *Improving Outcomes in Head and Neck Cancers*,¹⁷ published in 2004, commented that this is a group that includes many different types of disease, most of which are uncommon and some rare. The services necessary to care for people with these diseases are broadly similar in scope and in the expertise required. It was recommended that services for these cancers should be commissioned at cancer network level, and in the main serving populations of over 1 million people. MDTs with a wide range of specialists will be central to the service and each managing at least 100 new cases of upper aerodigestive tract cancer per annum.

Head and neck cancers can have devastating effects on the lives of patients; the treatment can be disfiguring and often makes normal speech and eating impossible. A wide range of support services should be provided, Home Introduction The challenge Prevention Earlier diagnosis Assessment Treatment services • Waiting times

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including local teams for patients who may need to travel to a specialist centre for their surgical treatment. Care co-ordination of this group of patients is crucial.

The British Association of Head and Neck Oncologists (BAHNO) has begun a process of nationwide audit, supported by the National Clinical Audit Support Programme (NCASP). This project, known by the acronym DAHNO (Data for Head and Neck Oncology), is now well established but data completeness and participation, however, are still limited in some areas.

The following are suggested issues that could be addressed by commissioners when looking for a high quality service.

Key commissioning questions for head and neck cancers	Where to find the answers
Team working	
What is the percentage of new or recurrent cases of head and neck cancer discussed at MDT?	Local provider/DAHNO
What is the percentage of head and neck cancer surgery performed outside a specialist team centre? (There should be none.)	HES
Does every surgeon in the specialist MDT who manages head and neck cancer spend at least 50% of their direct clinical care time on the management of cancer cases?	Local provider
Does every oncologist in the specialist MDT who manages head and neck cancer spend at least 50% of their direct clinical care time on the management of head and neck cancers?	Local provider
Do all services have co-ordinated local support teams to provide long- term support and rehabilitation for patients in the community?	Local provider and CQuINS
What percentage of patients has access to a clinical nurse specialist prior to the commencement of treatment?	Local provider and DAHNO

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Key commissioning questions for head and neck cancers	Where to find the answers
What percentage of patients receives a dental opinion prior to treatment? (Should be all – but often missing.)	Local provider
What percentage of patients receives pre-operative/pre-treatment (including radio and chemotherapy) dietetic assessment?	DAHNO
Waiting times/access	
Does the service see in excess of 100 new cases of head and neck cancers (upper aerodigestive tract – excluding thyroid and skin cancers) per year?	Local provider
Treatment	
What percentage of cases undergoing laryngectomy is offered choice of primary surgical voice restoration by a speech and language therapist prior to laryngectomy being undertaken?	Local provider
Is Intensity Modulated Radiation Therapy (IMRT) used for head and neck cancer cases?	Local provider
What proportion of patients undergoing chemo-radiation has residual disease following treatment? Of those, how many are offered salvage surgery? What proportion only receives palliative and supporting care? (There are alarming anecdotes and figures which suggest that some patients with potentially curative disease are only offered non-curative treatment.)	Local provider
What proportion of patients requires emergency surgery to reverse flap failure?	Local provider

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Key commissioning questions for head and neck cancers	Where to find the answers	
Length of hospital stay		
What is the average length of stay for patients with head and neck cancers with a surgical procedure?	HES	
Audit		
Does the team submit data to DAHNO?	Local provider/DAHNO	
Does the service regularly audit patients' experience in particular to seek views on their experience with practical, psychosocial and dietetic support during treatment and the recovery period?	Local provider	
What percentage of cases of head and neck cancer discussed at MDT has T, N and M staging data available?	DAHNO/local provider	

Further Clinical Lines of Enquiry are being developed by the NCIN Site Specific Reference Groups and peer review and this section with additional IOGs will be updated when these are available.

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6.3 Radiotherapy

6.3.1 What is radiotherapy?

External beam radiotherapy (teletherapy) is the delivery of radiation treatment to tumours, normally using a linear accelerator (linac). This is the most common form of radiotherapy and is the indicator included in the CCT. Other forms of radiotherapy include superficial treatment either by lower energy X-rays or electrons, normally intended to penetrate only a short distance; and brachytherapy, which involves the insertion of radioactive materials into the patient.

Radiotherapy is delivered by therapeutic radiographers under the direction of clinical oncologists and with critical input from physicists. Other key members of the workforce are dosimetrists (who play a key role in treatment planning and quality assurance) and technologists (who maintain equipment and fabricate patient and treatment accessories). Treatment is normally divided into a number of fractions to reduce the daily radiation dose given to the patient. Radical treatments consist of more fractions and are of longer duration than palliative treatments.

The positioning and shape of the treatment volume are critical. Treatment simulators and treatment planning computers are essential in planning precise treatment. The current generation of linear accelerators is capable of delivering precisely shaped treatment (conformal radiotherapy), which allows a higher dose to be given to the tumour while sparing the surrounding tissue.

Intensity Modulated Radiotherapy (IMRT) is a high precision form of radiotherapy. It conforms the shape and dose of the radiation precisely to the volume of tumour tissue that needs to be treated.

- The ability to precisely shape radiation dose to the tumour target means that the amount of radiation received by critical organs and normal tissues surrounding the tumour can be reduced or avoided. This reduces the toxic side effects of radiotherapy. By reducing side effects, higher radiation doses can be given, which may lead to increased tumour control rates in patients with certain cancers.
- IMRT therefore offers the following benefits:
 - Improved quality of life for patients, from reduced side effects
 - Potential to decrease medication costs, from reducing the need to manage long-term, serious toxicities
 - Potential to improve cancer control rates, from possible dose escalation.

Another example of high quality modern radiotherapy is Proton Beam Therapy (PBT). This is a very precise form of radiotherapy which can be effective in treating a number of cancers and avoiding damage to critical tissues near

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the tumour. This is particularly important in treating tumours near the central nervous system. Options for developing PBT facilities in England to treat up to 1,700 patients per year are currently being explored. However, these facilities will take time to develop. In order to ensure that all high priority patients with a need for PBT get access to this cutting-edge treatment, the National Specialised Services Team manages a programme that sends patients overseas for treatment. Based on an assessment of clinical need, this will benefit 400 patients per year by 2014/15, mostly children.

Expert advice indicates that over 50% of all cancer patients should receive radiotherapy as part of their cancer treatment.

6.3.2 Key issues/background

The Cancer Reform Strategy (2007) endorsed the recommendations of the National Radiotherapy Advisory Group (NRAG). NRAG's report was published in May 2007. This, together with the published NRAG subgroup reports, is the key best practice document for commissioners of radiotherapy services. All the documents are available at: www.ncat.nhs.uk/our-work/ ensuring-better-treatment/radiotherapy

Improving Outcomes: A Strategy for Cancer¹⁸ highlights that access to radiotherapy is critical to improving outcomes. It states that good information is essential as a way of benchmarking access to radiotherapy services. The Radiotherapy Data Set (RTDS) will be routinely published to ensure that commissioners and providers have benchmarked data about their performance; this data will also be reviewed to ensure that the metrics in the NRAG report remain meaningful and current.

Another important source of information to support service improvement is the NHS Improvement website. The NRAG report 2009 *Radiotherapy: developing a world class service for England* (www.ncat.nhs.uk) describes radiotherapy processes and provides a glossary of terms.

The key messages in the NRAG report are that:

- the projected need for radiotherapy was significantly underestimated 15–20 years ago. There is now a large gap (63%) between current activity levels and optimal treatment levels if radiotherapy were to be given to all who might benefit (see the Royal College of Radiologists (RCR) document on the evidence base for appropriate fractionation regimens at: www.rcr. ac.uk/docs/oncology/pdf/DoseFract_1-3.pdf)
- the gap between current activity levels and optimal treatment levels will worsen, since cancer incidence is set to increase by a third by 2020 owing to the ageing population

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- there are inequalities in access to radiotherapy treatment across the country, with a 2.5-fold variation in the number of fractions provided per million population between cancer networks (ranging from 17,500 to 48,000 fractions per million). This is also related to stage at presentation, where earlier stage disease that is more curable utilises a higher number of fractions. This also relates to the NAEDI work programme
- access rates to radiotherapy in England (i.e. the number of patients diagnosed with cancer who receive radiotherapy) currently stand at 38%, compared with other countries where 52% of patients receive radiotherapy at some time in their illness. This means that, of the 275,000 cancer patients diagnosed each year in England, 36,000 patients who might benefit from radiotherapy do not receive it
- the critical challenge is to ensure that the workforce is adequate to deliver increased radiotherapy, and more staff are being trained and more use needs to be made by centres of the four tier workforce model for radiotherapy, of assistants, practitioners, specialists and consultants. There is also a need to reduce attrition rates from those training in radiotherapy
- greater productivity could be achieved from linear accelerators if departments worked longer hours in the day and were open on more days

- waiting times for radiotherapy, where it is not the first treatment (and therefore not covered by the cancer 31 day and 62 day targets), remain long in some areas. There is evidence that this impairs treatment. For example, breast cancer patients who wait longer than eight weeks for post-operative radiotherapy have a 60% increase in local recurrence over five years (*British Medical Journal*, 2007, 34: 915). However, these waiting times are reducing as the 31 day target is being met
- providers of radiotherapy services to NHS patients should have a capital replacement programme in place. This also needs to ensure that equipment upgrades are included as appropriate.

Improved outcomes can also be delivered by ensuring that patients have access to high quality, modern radiotherapy techniques, comparable to those used in other European countries, to improve cure rates and improve patients' experience by minimising any longterm side effects of treatment.

To improve outcomes from radiotherapy treatment for cancer patients, commissioners should develop local plans to ensure that access rates to radiotherapy and the use of advanced radiotherapy techniques such as IMRT are appropriate for their populations.

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6.3.3 Performance indicators

The key metrics and performance indicators derived from the NRAG report to guide commissioners as to the appropriate levels of service for their population and what they might expect from their providers are as follows:

- by 2010/11, an interim goal of 40,000 fractions per million population should be delivered by radiotherapy services, recognising the fact that workforce and linear accelerator capacity needs to increase if expansion is to be achieved. (Note that this interim goal does not apply to London owing to population demographics; also note that this is an interim step measure, and is an underestimate of actual modelled need)
- by 2016, 54,000 fractions per million population (on average) should be delivered by radiotherapy services. (There may be some legitimate regional variation owing to differences in cancer incidence and stage of presentation.) Local modelling using the National Cancer Action Team ready reckoner (www.canceruk.net/downloads/ nrag) should be employed
- by 2016, approximately 52% of patients diagnosed with cancer should be treated with radiotherapy at some stage in their illness. This improvement in access rates relates to both clinical decision-making in acute services (appropriate

patient selection) and also to awareness and early diagnosis. Work with primary care pathways and the NAEDI initiative is vital to ensuring this access

- patients should receive routine radical radiotherapy within 31 days of being ready for treatment. Patients in need of palliative radiotherapy should be treated within 14 days; patients requiring urgent radiotherapy should be treated within 48 hours, as per RCR guidelines
- a radiotherapy service should be available within 45 minutes' travelling time for the majority of the population, although it is recognised that this may not be possible in all areas
- **linear accelerators should be replaced every 10 years** (a technical specification has been developed). Software should be upgraded every three years, to ensure accurate, high quality treatment. All replacement linear accelerators should be capable of Image Guided Radiotherapy (IGRT)
- linear accelerators should be used to best capacity:
 - 8,300 fractions per annum averaged across linacs in a department – by 2010/11
 - 8,700 fractions per annum averaged across linacs in a department by 2016.

The NRAG report offers advice to providers of services on how these levels of activity can be achieved.

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Print this page Print this section 41/56 A range of measures that focus mainly on governance, leadership and safety are also set out in the *Manual for Cancer Services*.¹⁹

Key questions commissioners should ask to assure themselves that they are commissioning high quality radiotherapy services are set out below.

A commissioning framework for radiotherapy can be found at: www.cancer.nhs.uk/radiotherapy/ commissioning.htm. It comprises three documents:

- generic patient pathway
- contracting framework
- service specification.

These tools are designed to support commissioners in ensuring consistency and wider understanding of the key parameters.

Key commissioning questions for radiotherapyWhere to find the answersActivity and accessHow many fractions of radiotherapy are being
delivered per million population served?Local contracts if fractions used as currency; national
radiotherapy equipment survey (2008/09); Outpatient
Commissioning Dataset (OPCDS) to support
Healthcare Resource Group (HRG) v4 for radiotherapy;
National RTDS – commissioners can get access via their
cancer network director

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Provider services are expected to make monthly uploads of data to the RTDS. This data will help commissioners to benchmark and analyse local position.

www.ncat.nhs.uk/our-work/ensuring-better-treatment/ radiotherapy is the NCAT website with a wealth of resources for commissioners and networks in developing their radiotherapy processes and provision.

The RTDS is now available online with local and national analysis. Access to this is via the local cancer network director. The RTDS will provide analysis and benchmarking of services. Home Introduction The challenge Prevention Earlier diagnosis Assessment

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Key commissioning questions for radiotherapy	Where to find the answers
If this is less than 40,000 fractions/million, what is the key limiting factor (e.g. staff, machines or both)? (Note that this excludes London.)	Local provider RTDS Note that this also relates to stage of presentation and to MDT pathways Note that a new modelling tool (which will more accurately enumerate local planning forecasts) is under development, and will be available in October 2011
What proportion of cancer patients in this locality/ network receives radiotherapy? (It should be around 50%.) (Note that even if waiting times are being met, it is important to ensure that all patients have access to radiotherapy where appropriate, and that they also have access to appropriate levels of treatment.)	This can be measured by comparing the incidence of cancer (from cancer registry) with the numbers of patients treated with radiotherapy, but excluding those being re-treated (local services department). The current result of 38% in England indicates limited access Note that analysis of data upstream from the radiotherapy service will also be of use. NAEDI work and MDT decision-making are key determinants here. This will allow commissioners to more easily identify local requirements
What proportion of patients has to travel longer than 45 minutes to access radiotherapy? Do any significant concentrations of population travel further than 45 minutes?	Mapping data from the National Cancer Services Analysis Team (NatCanSAT) or local GIS mapping of patient postcodes
Does the network/unit have a realistic plan to deliver the NRAG recommendations?	Local plan in place

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Key commissioning questions for radiotherapy	Where to find the answers	
Is the service being commissioned by disease care pathways? Are service specifications in place?	Documentation supporting the development of service specifications by care pathways can be found at: www.ncat.nhs.uk/our-work/ensuring-better-treatment/ radiotherapy	
Waiting times		
Are the current 31 and 62 day standards being met where radiotherapy is the first and subsequent treatment?	Cancer waits database Local delivery plan for 31 day subsequent radiotherapy	
What proportion of local patients waits longer than 31 days for radical treatment?	Royal College of Radiologists National Audit 2007 RTDS from April 2009 onwards, peer review measures	
What proportion of local patients waits longer than 14 days for palliative treatment?	Royal College of Radiologists National Audit 2007 RTDS from April 2009 onwards	
Quality		
Is there a network group for radiotherapy services?	Local network Note that the National Cancer Action Team has provided a template for the network radiotherapy group to facilitate local analysis of patient flows and equitable service access	
How well do current service providers comply with peer review measures? Are agreed-quality Serious Untoward Incident reporting systems in place? Is action being taken to remedy deficiencies?	CQuINs, local systems, Serious Untoward Incident reporting	
Are there agreed dose fractionation regimes within the service and network?	Local policies	

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6.3.4 Best practice on planning for service expansion

If service expansion is needed to ensure access to appropriate levels of radiotherapy for the population, commissioners will want to review the options:

- What is the increase in fractions required for the population by 2016? (To make good any shortfall in provision and address increasing incidence.)
- Can the total of, or a proportion of, the required increase in activity be provided through more efficient use of the existing linacs? (See NRAG recommendations pp. 18–22; this solution is likely to require longer working hours and more radiographers and other staff.)

If additional linear accelerators are required to deliver an appropriate level of fractions to the population:

- Has the lack of access to radiotherapy services been identified in a commissioner's/local authority Joint Strategic Needs Assessment and has the additional need for radiotherapy been systematically quantified by assessing local tumour incidence, stage of presentation and recommended fractionation regimes (see methodology in NRAG report)?
- Have appropriate processes been put in place to engage the views of users, the local community and, if appropriate, Overview and Scrutiny Committees (OSCs)?

- Is there a case for developing an ambulatory satellite radiotherapy service in addition to the existing service/centre in order to improve access to significant concentrations of population who live 45 minutes or more from the current service? This may be most appropriate for the delivery of routine radiotherapy, e.g. breast, prostate, lung. (Note that satellite/ devolved services should always be developed in a way that facilitates integrated working with the existing providers of radiotherapy services, that uses the workforce most effectively and that allows subspecialisation among oncologists to be maintained across the cancer network. See the RCR publication Guidance on the Development and Management of Devolved Radiotherapy Services.²⁰)
- Are there benefits in increasing linac capacity at the current centre (e.g. through more effective use of existing staff)?
- Have network plans for the expansion of radiotherapy services been discussed with neighbouring networks through the specialised commissioning groups (SCGs) or SHAs to ensure that there is a 'good fit' for planned developments across the SCG, and that proposals do not impact on other network flows for services, potentially undermining the critical mass required for specialist services?

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20 www.rcr.ac.uk/docs/oncology/pdf/Management_Devolved_Radiotherapy_Services.pdf

- Is the DH best practice for commissioners on procurement of services being followed?
- Has consideration been given to the opportunity to explore innovative solutions that maximise ambulatory care and local access to cancer services in addition to radiotherapy, e.g. chemotherapy, diagnostic equipment, information centres, supportive care?
- Do specifications/contracts with providers set out clearly when they are expected to be delivering radiotherapy services that meet the key performance indicators?

More detailed best practice and guidance on planning for service expansion has been circulated to the service.

6.4 Systemic anti-cancer therapy

6.4.1 What is systemic anti-cancer therapy?

The use of systemic anti-cancer therapy (this includes chemotherapy, monoclonal antibodies and small molecule targeted agents but is referred to for simplicity as 'chemotherapy' throughout this section) has increased markedly over the past decade. The medical treatment of cancer involves the use of several distinct groups of drugs:

• cytotoxic drugs – these are the original anti-cancer drugs and include alkylating agents, cytotoxic antibiotics, vinca alkaloids and antimetabolites.

More recent drugs such as platinum drugs and taxanes also fall into this group

- drugs affecting the immune response this group includes corticosteroids and other immune suppressants, interferon and the new monoclonal antibody drugs
- hormones and hormone antagonists hormone manipulation has an important role in the treatment of breast, prostate and endometrial cancer. This group includes oestrogens, progestogens, anti-androgens and more recent drugs such as aromatase inhibitors
- supportive drugs which do not have a direct anti-tumour effect – this group includes marrow stimulating drugs, calcium-lowering agents and specialised anti-emetics. Complex antibiotic regimens also have an important role where treatment has resulted in marrow damage and a low resistance to infection.

Chemotherapy is given in standard, internationally recognised regimens, often containing a combination of drugs. Treatment is prescribed by medical and clinical oncologists and haemato-oncologists and delivered by specialist chemotherapy nurses. The drugs for injection are prepared to an individual prescription by trained pharmacists using sealed cabinets, which minimise hazards.

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Print this page Print this section 46/56 Most regimens continue over several months and involve mainly day case attendance at a specialist clinic, or in other ambulatory care settings. Some treatments are also given in combination with radiotherapy. In order to be effective, many drugs are given at the maximum dose tolerable and significant side effects should be anticipated. Some patients will encounter life-threatening side effects and will require emergency readmission to a specialist unit. Some regimens, along with hormones and hormone antagonists, may be continued in a community setting including patients' homes.

6.4.2 Key issues/background

Improving the quality and safety of chemotherapy services can make an important contribution to delivering on the patient safety domain of *The NHS Outcomes Framework 2011/12*.²¹ Commissioners will need to ensure that they have robust and fair processes in place for making decisions on drugs that have not yet been approved by NICE. Commissioners will also need to take account of current processes in place locally around the administration of the Cancer Drug Fund.

Commissioners should also take into account documents such as the guidance on intrathecal chemotherapy (www.dh.gov.uk/prod_consum_dh/ groups/dh_digitalassets/documents/digitalasset/ dh_086844.pdf) and guidance on the use of minibags to administer vinca alkaloids (www.nrls.npsa.nhs.uk/ resources/type/alerts/?entryid45=59890&p=2).

NHS commissioners may wish to use financial incentives and contractual arrangements to improve quality and choice, to encourage reductions in emergency admissions and to reward improvements in patient experience. To achieve this NHS commissioners may wish to set requirements about the introduction of e-prescribing, door-to-needle time for patients with neutropenic sepsis and acute oncology services (these last two are shown as possible CQuIN projects for 2011/12).

6.4.3 NCAG report

The NCAG report²² (August 2009) provides best practice guidance for commissioners of chemotherapy services. The report sets out a framework for planning, implementing and monitoring services based on a care pathway model and proposed actions that need to be taken by commissioners and providers to ensure high quality care.

The challenges facing commissioners include how to respond to the:

 historic variation in accessibility and organisation of services

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 $\label{eq:21} www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944$

22 www.cancer.nhs.uk/chemotherapy/ncag.html

- accelerating demand for systemic therapy
- advances in stratified medicines
- toxicity of treatment and the growing need for the effective management of complications, particularly out of hours
- variation in the use of inpatient beds for delivery of chemotherapy and the opportunity to liberate resources through a greater ambulatory approach
- better use of new technologies (e.g. supportive drugs to reduce complication rates, oral rather than intravenous treatments)
- need for adequate capacity to deliver chemotherapy (workforce and facilities)
- complexity of the pathway across providers and the need to secure continuity of care, with a clear governance framework to ensure patient safety.

Commissioning strategies should be built on a baseline assessment of the provision of chemotherapy for a population, including a review of the:

- drugs/treatments offered, against both NICE recommendations and other national evidence
- distribution and population coverage of the service
- environment in which the service is offered
- skills and capability of the teams in supporting patients who are faced with toxic treatments that have a wide range of challenging side effects
- impact services are having on patients' quality and quantity of life.

Commissioners will want to be particularly aware of the following key recommendations for best practice from the NCAG report. The full text of these and all NCAG recommendations can be found at: www.dh.gov.uk/en/Publicationsandstatistics/ Publications/DH_104500

Acute oncology: All hospitals with emergency departments should establish an acute oncology service (AOS), which brings together the necessary expertise from emergency medicine, general medicine and oncological disciplines.

Assessment, decision to treat and consent:

Decisions on the initiation of a programme of chemotherapy should be made at consultant level unless there are exceptional circumstances, which should be documented. Patients should be fully involved in decisions regarding their care and treatment. Standardised consent forms should be used.

Prescribing and dispensing: Prescribing, prescription verification and dispensing of chemotherapy should only be undertaken by appropriately trained staff. All chemotherapy services should maintain up to date lists of staff that are designated to prescribe (either first or subsequent cycles), check prescriptions and dispense chemotherapy. Protocols should be agreed across a cancer network and incorporated into a protocol 'book'.

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Delivery: All cancer networks should undertake rigorous capacity planning. The C-PORT chemotherapy planning tool can facilitate this. Inpatient delivery of chemotherapy should be minimised. Where clinically appropriate, chemotherapy services should be localised.

Information, education, support and advice:

All patients should be given both verbal and written information about their treatment, likely side effects and whom they should contact if problems arise (either within or outside normal working hours). All patients should have access to 24-hour telephone advice with active management of access to appropriate emergency care.

Urgent assessment and management of

complications: Patients should know which hospital/ unit to go to should they develop complications within or outside normal working hours. AOSs should have clear and readily accessible policies for managing complications including neutropenic sepsis.

Febrile neutropenia: Each Trust must have its own regularly updated policies and procedures for the treatment of patients suffering febrile neutropenia as a consequence of chemotherapy.

Leadership: Effective leadership is needed at Network and Trust levels for both elective chemotherapy services and acute oncology. All NHS Trusts providing elective chemotherapy and/or acute oncology should ensure they have appropriate leadership teams in place.

Clinical governance: Each chemotherapy service needs to ensure that the protocols and policies described in this report are developed, implemented and regularly audited. Each chemotherapy service must have regular morbidity/mortality meetings to review practice, policies and procedures in relation to the safety and quality of chemotherapy.

Data collection: The National Cancer Intelligence Network (NCIN) is leading work to define a national chemotherapy dataset in association with members of the National Chemotherapy Implementation Group. Once approved, collecting the new dataset will be mandatory as set out in Improving Outcomes: A Strategy for Cancer, from April 2012.

Information technology: Those chemotherapy services which do not currently use electronic prescribing should strongly consider doing so at the earliest opportunity.

6.4.4 Actions for commissioners

Commissioners should work together across a cancer network to plan, procure and monitor service delivery. They should ensure that AOSs are available in all hospitals with A&E departments. If chemotherapy is given elsewhere, commissioners should ensure that there are

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appropriate arrangements in place for patients to access telephone advice and emergency care. They will wish to achieve an appropriate balance between centralisation and localisation and to ensure that all services deliver safe and effective services in line with NCAG guidance.

Commissioners of chemotherapy services should ensure that:

- patients who might benefit from chemotherapy are able to **access** quality services
- treatments that are delivered are **appropriate** to a patient's condition
- services are delivered **safely**
- services are **convenient** for patients
- patient experience is good
- services represent good value for money.

Commissioners in the cancer network, supported by their cancer network teams, should undertake a baseline assessment of chemotherapy provision across the network, review its appropriateness and develop a strategic framework for chemotherapy delivery, setting out what chemotherapy should be given where in line with the recommendations of the NCAG report and giving consideration to patient choice of location.

Commissioners across the cancer network should assure themselves that they have sufficient expert advice to

guide their commissioning in this high cost, complex area. Investment in expertise will lead to savings from the rationalisation of chemotherapy provision and reduced complications from chemotherapy treatment.

Commissioners should develop collaborative procurement agreements that are sensitive to local needs and consider agreeing a lead cluster for commissioning services on behalf of commissioners across the network. The National Cancer Action Team has developed a service specification for chemotherapy to reflect the key recommendations and best practice set out in the NCAG document. This can be found on NCAT website at: www.ncat.nhs.uk/our-work/ensuringbetter-treatment/chemotherapy

Commissioners will need to agree the most appropriate model of contract for promoting an integrated network of chemotherapy service provision, and governance that ensures continuity of clinical care across provider boundaries. Contracting with a lead provider or a formalised consortium of providers is strongly recommended in view of the movement of both patients and core clinical staff between organisations.

Commissioners should work with network teams to ensure that choice of setting for delivery of chemotherapy offers patients the opportunity to receive care as close to home as possible.

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Print this page Print this section As a matter of best practice, the NCAG report states that commissioners should assure themselves that providers have agreed clear responsibilities regarding AOSs and clinical leadership of chemotherapy services, as well as how information on patient treatment will be accessible across the network of service provision. These arrangements should be in place by 2011.

Commissioners in the cancer network should agree a network-wide chemotherapy protocol book (actual or web-based) and specify its use with providers. Commissioners should formalise and publish their collective arrangements for making decisions about the introduction of new drugs/new drug indications in line with best practice advice.

An annual assessment of the impact of the introduction of new drugs should be made with providers, using supportive tools such as the Horizon Scanning Module in the CCT. Commissioners should assure themselves that providers are planning appropriate capacity through the use of C-PORT or an equivalent capacity planning tool. The quality of the environment for giving chemotherapy should also be assessed.

Commissioners should review the level of emergency admissions for cancer patients, including those with complications following chemotherapy. Commissioners, supported by their networks, will want to work with providers to ensure that new models of care are put in place to address these (acute oncology teams (AOTs), community support, proactive management of patients, patient education). Once new models of care are in place it will be helpful if thresholds to reduce nonelective admissions are explicitly agreed in contracts with providers.

In addition, commissioners should monitor the overall proportion of cycles of treatment delivered on an inpatient or day case basis; and the proportion of treatment cycles given at a cancer centre, cancer unit or community/home setting.

Commissioners should specify the need for information systems to be put in place, both to support the management of patient care (such as e-prescribing) and to record activity and costs across the network of service provision. Commissioners should ensure that coding and costing to support Healthcare Research Groups (HRG) v4 are in place in all providers of chemotherapy services with immediate effect.

Commissioners should work with providers to prepare for the implementation of tariff in 2012/13. This will require a year of shadow running against their current contracting methodology, followed by a year of using local costs applied to the national HRG framework, before full tariff is implemented.

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Print this page Print this section 51/56 Commissioners will want to agree a migration path with providers to collect the full chemotherapy dataset when it is published. The draft is currently available (www.ncat.nhs.uk/our-work/ensuring-better-treatment/ chemotherapy), and it is hoped that the change notice from the Information Standards Board will be issued during the summer of 2011. They will also want to specify a requirement for reports on incident trends and an annual quality report to be made available for network-wide review.

Key questions commissioners should ask to assure themselves that they are commissioning high quality chemotherapy services are set out below.

Key questions for commissioners	Where to find the answers
The chemotherapy pathway	
What proportion of patients admitted as emergencies is seen by an oncologist within 24 hours of admission?	Patient records HES data NHS Improvement – Winning Principles
Assessments and decision to treat	Local patient surveys (the new national cancer patient survey will help) Audit of consent procedures Documentation of attendance at communication skills courses
Audits of off-protocol usage	Local audit
Proportion of prescriptions hand-written, pre-printed	Local audits or review of local records
Capacity – is there agreement about which regimens may be delivered at each service? What is each service's spare capacity?	C-PORT or other capacity tool
Are 24-hour helplines in place? Do helplines have access to current information about the patient's condition and chemotherapy treatment?	Local audits or review of local records

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Key questions for commissioners	Where to find the answers
What proportion of patients with suspected neutropenic sepsis receives treatment within an hour?	Local audit
How many patients/GPs receive a summary record at the end of treatment?	Local audit
What was the percentage compliance/gap when networks were asked to self-assess against chemotherapy peer review measures?	CQuIN
Which trusts have e-prescribing systems for all chemotherapy given? Is there a network-wide chemotherapy protocol book?	Network-wide regimen protocols CQuIN/local review
How robust are processes in trusts to collect data?	Local review
Review of deaths within 30 days of administration of chemotherapy	Hospital morbidity and mortality review meetings/ audits and notes reviewed/HES
What mechanisms are in place to support collaborative decision-making around chemotherapy across the network?	Local records
Across the cancer network do explicit/documented provider-to-provider agreements about mutual responsibilities and governance arrangements exist?	Local records

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Key questions for commissioners	Where to find the answers
Are readmissions following chemotherapy administration monitored? Is there information about what proportion of chemotherapy is given on an inpatient as opposed to day case basis? Are beds being appropriately used?	HES Local records
Is there an explicit strategic framework in place across the cancer network for the delivery of chemotherapy?	Local records
Are there adequate chemotherapy service level agreements/specifications in place between commissioners and trusts?	Local records
Is there an agreed project plan and are supporting arrangements in place to deliver HRG v4 for chemotherapy?	Local records

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6.4.5 Best practice on planning for service expansion

There continues to be concern nationally about a lack of service capacity to support the rise in demand for chemotherapy. This includes insufficient chemotherapy nurses, too little space to administer therapy and, in many cases, limitations on pharmacy capacity to supply the drugs in a safe and timely way.

Managing resources better

In some parts of the country, NHS trusts/foundation trusts are exploring a range of scheduling and capacity tools to see how they can maximise benefit to the patient and use their resources more effectively. The roll-out of the national capacity modelling tool, C-PORT, offers a means of benchmarking provider performance across the country.

This tool can also help with planning for the introduction of new drugs, including mapping changes in activity levels and understanding the impact of replacing intravenous with oral treatments.

Most patients should be able to receive their chemotherapy in an ambulatory setting – ranging from cancer centres to local hospitals or, in some cases, their own home. Inpatient care for both solid tumour and haemato-oncology patients should only be for those most vulnerable patients who may require very complex treatment.

New workforce models are also emerging, with extended roles for both nurses and pharmacists.

Adding capacity

Traditionally, the main providers of NHS-funded chemotherapy services have been NHS oncology centres and local hospitals. In some parts of the country, however, commissioners and the independent sector have both become involved in the provision of chemotherapy, particularly in community and home care.

The expansion of new entrants for providing this service could be an option in areas where there are capacity constraints or where there is a need for new ways of working that offer a different philosophy and added value to the patient experience (e.g. alongside more supportive care).

In some cases, the use of external providers for drug preparation can also offer economies to a local health community.

6.4.6 Targeted medicines

Advances in knowledge of genetics and biochemical pathways are now being translated into new targeted drugs. Suitable patients are identified through a variety of tests. An example of this includes the HER2 test which predicts whether a breast cancer patient will respond to trastuzumab or lapatinib.

Commissioners should be aware that the Department of Health has established a new programme – the Stratified Medicines Innovation Platform. This will be targeting research and development in a number of areas, and this section will be updated to reflect work coming from this programme.

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6.5 Cancer Commissioning Toolkit metrics

The CCT contains the following related metrics. These can be found by accessing the corresponding chapter **Treatment** and sections **Waiting times**, **Radiotherapy**, **National audit participation** and **Cancer medicines**, either via the dashboard or the contents page.

Waiting times

- Two week wait performance
- Two week wait exhibited non-cancer breast symptoms performance
- Two week referral (TWR) performance trend by PCT/network
- TWR performance time series by trust
- Percentage TWR with cancer diagnosis
- Number of TWR with cancer diagnosis

31 day standard performance

31 day standard performance time trend by SHA/PCT/ network

31 day standard performance time trend by trust

Percentage of all cancer cases **not** referred as TWR Percentage of all cancer cases **not** referred as TWR, time trend Percentage of all cancer cases **not** referred as TWR, time trend by trust 62 day performance 62 day standard performance, time trend bySHA/PCT/network62 day standard performance time trend by trust

Radiotherapy

Number of radiotherapy fractions per million population Average fractions per linear accelerator per year

National audit participation

National audit participation (NCASP)

Audits include:

NBOCAP (bowel) DAHNO (head and neck) NLCA (lung) NMBRA (National Mastectomy and Breast Reconstruction Audit) Oesophago-gastric

Cancer medicines

Horizon scanning Drug cost Projected cost of upcoming NICE approvals Projected cost of upcoming Scottish Medicines Consortium (SMC) approvals Projected costs of upcoming All Wales Medicines Strategy Group (AWMSG) approvals Activity planning Activity planning – cost and volume graph (now in section 1)

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7. Commissioning to transform cancer inpatient care and move to ambulatory models of care

7.1 Background

The Operating Framework for the NHS in England 2011/12 provides direction for PCTs/GP consortia to continue to deliver on service quality and to ensure that they can deliver efficiencies to realise substantial savings that can then be re-invested. The National Audit Office 2010 report *Delivering the Cancer Reform Strategy* reported that good progress had been made in reducing the number of inpatient days and that the rise in emergency admissions had been slowed down. However, there is further work to do. The Transforming Inpatient Care Programme, which was established when the *Cancer Reform Strategy* was produced, is promoting:

- day case/one night stay for breast surgery and other procedures
- enhanced recovery programmes for elective cancer surgery
- approaches to reduce avoidable admissions
- reducing lengths of stay for those who need to be admitted as emergencies.

The programme is underpinned by four fundamental principles:

- 1. Emergency/urgent patients should be assessed prior to the decision to admit. Emergency admissions should be the exception, not the norm.
- 2. All patients should be on a defined pathway based on their tumour type and reason for admission.
- 3. Clinical decisions should be made on a daily basis to promote proactive case management.
- 4. The patient and carers need to know about their condition and symptoms to encourage self-management.

Improving Outcomes: A Strategy for Cancer (IOSC) confirms the importance of focusing attention on inpatient care. Too many patients are being admitted into hospital and lengths of stay are often unnecessarily prolonged. A review of HES data for 1997/98 to 2008/09 (cancer episodes) has further shown that:

- day cases (including RNA and RDA) have increased over a 12 year period from 0.5m (522,453) to 1.3m (1,251,000 – 09/10) (+140%)
- emergency admissions (episodes) have increased by 70% over the 12 year period
- total bed days peaked at 5.29 million in 2005/06. Since then there has been a 10% fall to around 4.7 million (to 2008/09, or -11% to 2009/10)

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- total reduction (to 2009/10) in bed days from the peak in 2005/06 = 571,000
- most emergency bed days (>75%) are under the care of medical and surgical specialties, not oncology or haematology
- inpatient admissions (episodes) for cancer rose by 25% between 1997/98 and 2005/06, but in the past four years had only increased by 4% (from 2005/06 to 2009/10).

The number of bed days rose, on average, by 1% each year between 1997/98 and 2005/06, but then dropped in the past four years by 11% (from 2005/06 to 2009/10). On any single day, some 13,000 cancer patients are in a hospital bed. This equates to around 24 occupied beds per 100,000 population, and around 360 beds occupied by patients with cancer in an average sized network with a population of 1.5 million. If bed occupancy were maintained at 80%, this would be the equivalent of 450 hospital beds in an average sized network dedicated to the treatment of cancer patients each day.

The overarching aim of the programme is to 'improve quality and save a million bed days'.¹

The Transforming Inpatient Care Programme provides practical support to organisations and are outlined below.

 Reduce the length of elective surgical admissions and associated readmissions. Enhanced recovery approaches help patients to recover sooner from surgery by ensuring that they are in the best possible condition for surgery, receive optimal management during and after surgery, and experience the best possible postoperative rehabilitation. Through this approach, enhanced recovery improves quality of care and patient experience while also improving productivity. A key principle of the approach is to ensure that patients are fully informed and involved in decisions about their care and therefore more able to self-manage and to access the help and support they require. SHAs are leading implementation of this approach locally, working closely with cancer networks. It covers cancer patients in colorectal, urology and gynaecology departments and also patients having musculoskeletal surgery. Further information for commissioners is available on the NCAT website: www.ncat.nhs.uk/our-work/improvement/ transforming-care-for-inpatients²

The day case one night stay breast pathway supports patient choice, reduces unnecessary lengths of stay in hospital and promotes patient self-management. This model of care builds on the principles of day case best

1 Department of Health (2009) Cancer Reform Strategy: Achieving local implementation – Second annual report, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109338

2 Information is also available on the NHS Improvement website: www.improvement.nhs.uk/enhancedrecovery

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practice and is being promoted through 13 National Clinical Spread Networks across England as part of the Transforming Inpatient Care Programme. Further details are available on the NHS Evidence website at: www.library.nhs.uk//qipp/ViewResource. aspx?resID=396552

• Reduce the number and length of elective medical admissions, particularly those under haematologists or medical/clinical oncologists, and in some instances avoiding inpatient admissions altogether by providing care in ambulatory settings. The local cancer network team, in collaboration with oncology centres and haematology services, will be well placed to support this. These specialties account for 25% of all elective cancer admissions.

Shifting procedures to ambulatory settings: traditionally many procedures such as Hickman line insertion, blood transfusions, acsitic drains, computerised tomography insertion biopsy, ultrasound guided biopsy, high dose rate full insertion and intravenous antibiotics have been carried out as an admission into inpatient beds, particularly in haematology and oncology. Applying the principles of day case good practice, such procedures can be delivered without admitting the patient into a hospital bed. This values the patient time and releases bed capacity. • Reduce the number of emergency/urgent admissions due to side effects of treatment (such as chemotherapy or radiotherapy) or progressive disease. The aim is that, with more proactive emergency and urgent care pathway risk management and promotion of patient selfmanagement, patients' symptoms, side effects and acute episodes of ill health can be identified early and managed on an ambulatory basis. Commissioners need to be closely involved in this aspect of the work to establish emergency/urgent care pathways, for example symptom pathways for the management of pain, breathlessness, urinary retention and febrile neutropenia. Cancer networks' service improvement teams can support acute trusts and community providers to put in place pathways to proactively manage emergency and urgent care in order to avoid inappropriate admissions and reduce overall length of stay.

This area of improvement also complements and supports work in survivorship as a continuum of quality improvement. Further comments on this topic are covered in chapter 6: Commissioning improved treatment services, and contain specific areas that services need to take account of, including recommendations from the National Confidential Enquiry into Patient Outcome and Death – Systemic Anti-Cancer Therapy, and the National Chemotherapy Advisory Group (NCAG) report.

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Print this page Print this section • Support the more rapid diagnosis of patients presenting with symptoms that may be due to cancer. Please refer to chapter 4: earlier diagnosis for further information.

Commissioners will also want to consider use of the CQUIN exemplar goals. These can be found at: www.institute.nhs.uk/world_class_commissioning/ pct_portal/cquin.html

7.2 Why focus on inpatient care?

- It matters to patients.
- Most patients have at least one admission during their treatment – it is an opportunity to improve the patient experience.

Two thirds of patients who responded to the 2010 Cancer Patient Experience Survey expressed confidence and trust in ward nurses treating them, but this figure can be improved.

Expanding patient choice across the pathway will be important to ensure that we achieve choice in line with *Liberating the NHS: Greater choice and control* (DH, 2011).

7.3 Inpatient stays and emergency admissions

The Transforming Inpatient Care Programme is concerned with valuing patients' time and effectively managing and using resources.

- It is recognised that England has a high bed utilisation for cancer. Diagnosed cancer accounts for 12% of all inpatient bed days in England. Inpatient costs account for a large proportion of the total cancer expenditure, and reducing inpatient bed days/admissions provides an opportunity to redirect resources into other areas of cancer care.
- Inpatient admissions for cancer rose by 25% between 1997/98 and 2005/06 but in the past four years have increased by 4%. The number of bed days rose by 1% each year between 1997/98 and 2005/06 but in the past four years has dropped by 10.8%.
- In 2008/09 on any single day, some 13,000 cancer patients were in a hospital bed, and in 2009/10 12,930 cancer patients were in a hospital bed. This equates to around 24 occupied beds per 100,000 population, and around 360 beds occupied by patients with cancer in an average sized network with a population of 1.5 million. If bed occupancy were maintained at 80%, this would be the equivalent of 450 hospital beds in an average sized network dedicated to the treatment of cancer patients each day.
- It is important to recognise that the majority of cancer inpatients are under the care of general medicine, care of the elderly or surgery. Lower numbers are under the care of haemato-oncology, clinical oncology or medical oncology.

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The tables below show cancer admissions using HES data for 1997/98 to 2009/10.

	1997/98	2005/06	2008/09	2009/10
Day cases (including RDA/RNA)	522k	965k (+85%)	1,186k (+23%)	1,251k
Elective/ordinary				
Episodes	347k	375k (+8%)	350k (-7%)	343k
Bed days	2,313k	2,167k (-6%)	1,888k (-13%)	1,826k
Average length of episode	6.7	5.8	5.4	5.3
Emergency				
Episodes	277k	407k (+47%)	443k (+9%)	471k
Bed days	2,612k	3,113k (+19%)	2,852k (-8%)	2,889k
Average length of episode	9.4	7.6	6.4	6.1
Total inpatients				
Episodes	627k	783k (+25%)	795k (+1%)	814k
Bed days	4,950k	5,290k (+7%)	4,745k (-10%)	4,719k
Average length of episode	7.9	6.6	5.8	5.7

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Emergency admissions by specialty	1997/98	2005/06	2008/09	2009/10
Medical and surgical				
Episodes	207k	320k (+55%)	345k	364k
Bed days	1,945k	2,392k (+23%)	2,205k	2,202k
Average length of episode	~9.4	~7.7	~6.4	~6.0
Oncology				
Episodes	38k	51k (+34%)	56k	60k
Bed days	300k	393k (+31%)	387k	404k
Average length of episode	7.9	7.7	6.9	6.7
Haematology				
Episodes	24k	26k (+8%)	27k	30k
Bed days	197k	221k (+12%)	215k	229k
Average length of episode	8.0	8.4	7.7	7.6

• 27% of inpatient costs relate to non-surgical stays (excluding the costs of drugs).

• 22% of inpatient costs relate to surgery (including day cases and inpatient stays).

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Over the next 15 years, the incidence of cancer is likely to increase by around 24% (based on current trends) and this will put further pressure on inpatient cancer services. Hence, in order to keep inpatient costs at the same level:

- the average length of stay must fall by one quarter or
- approaching half of all emergency admissions would have to be avoided.

The large majority of cancer patients do not want to be admitted to hospital unless it is absolutely necessary, and when they are admitted they want it to be for as short a time as possible.

In November 2010, the National Audit Office (NAO) published *Delivering the Cancer Reform Strategy*, a value for money study examining progress in three key areas of action announced in the *Cancer Reform Strategy*: improving the quality of information, strengthening commissioning and making better use of resources.

The NAO report, while noting that good progress had been made in reducing the number of inpatient days per year, also noted that admissions per new cancer diagnosis varied from 1.7 to 3.2 between PCTs during 2008/09. If every PCT/GP consortium met the inpatient admissions per new cancer diagnosis of the best performing quartile, 532,000 beds days could be saved. There is scope to go further with this action and it would make a significant contribution to the efficiency savings that the NHS needs to make.

The NAO also reported that average length of stay for inpatient cancer admissions varied from 5.1 to 10.1 days between PCTs in 2008/09. If every PCT/ GP consortium had the same length of stay as the average in the best performing quartile, then even with no overall reduction in inpatient admissions, 566,000 bed days could be saved, with a saving of around £113 million each year.

As stated in Improving Outcomes: A Strategy for Cancer, the National Cancer Programme (NCP) will be working to collate and publish information on admissions, lengths of stay and bed days by commissioner and by provider trust; this information is available through the Cancer Commissioning Toolkit (CCT).

The CCT provides benchmarked information to support analysis of all the above areas, enabling networks and commissioners to gain an overview of their local bed usage. It also provides signposts to supportive information on tested improvements that can be adopted to improve the quality and efficiency of the inpatient pathway.

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7.3.1 Outcomes

There are a number of principles that the Transforming Inpatient Care Programme will focus on:

- improving outcomes and improving the pathways that deliver care by adopting the best practice available
- enhancing quality of life for people with cancer
- helping people to recover from episodes of ill health so they can get back to normal as soon as possible.

7.4 Commissioning starting point

The starting point is to develop an overview of local bed use on a resident and provider basis. The CCT is a resource that provides relevant inpatient data.

Commissioning organisations will want to undertake a baseline assessment, and some suggested questions are shown below:

- How many beds in the hospital/trust does a cancer patient occupy on any one day (emergency and elective)? (Source: HES occupied beds (i.e. total bed days due to cancer in a year ÷ 365)/CCT)
- How many bed days/beds does this amount to each year (emergency and elective)? (Source: HES)

- How many emergency/elective finished consultant episodes (FCEs) each year of the total trust activity are due to cancer as a measure of the proportion of activity cancer represents for the trust?
- What is the difference across the tumour types for all the above (percentage share)?
- Which specialties are responsible for managing inpatients with cancer?
- What is the average number of excess bed days above the HRG trim point (emergency and elective benchmarked) per admission?
- What is the approximate cost of cancer inpatient care in the trust in total and for each type of tumour?
- How many intensive therapy unit/high dependency unit (ITU/HDU) beds are used for patients with cancer?
- What proportion of the hospital/trust's activity is due to cancer in each specialty?
- What national/local information is there about cancer patients' experience of inpatient care, for example for haematology and oncology services in each trust?
- Have patients' views about their inpatient experience been surveyed?

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7.5 Developing a local overview of cancer inpatient care for the resident population of the commissioning body/cancer network

7.5.1 Key commissioning questions

- How many bed days can be saved if the trust or trusts in the network operate at the upper quartile performance for length of stay in key operations? How can bed capacity be released and savings reinvested elsewhere?
- Where can the greatest gains be made, by trust or by type of tumour? How can things be done differently?
- How can the length of stay be reduced?
- Can care be provided in alternative ways (for example moving from inpatient to day case to outpatient to home)?

7.5.2 Metrics

Benchmarked length of stay by specific procedures – by trust/network (provider) detailing:

- pre-operative length of stay
- post-operative length of stay
- bed days above HRG trim point and cost
- upper quartile performance calculation regarding potential bed savings.

Quality/efficiency indicators include:

- days in ITU/HDU
- readmission rates and complications.

7.5.3 Suggested key actions

Shown below are a number of models and approaches that are in use by services where length of stay has successfully been reduced.

- Implement enhanced recovery approaches in colorectal, gynaecology, urology and musculoskeletal surgery.
- Develop pre-admission clinics/systems.
- Ensure that diagnostic tests are completed prior to admission.
- Same day admission for surgery.
- Plan and ensure an integrated discharge package; refer early to other supportive agencies.
- Ensure that complex discharge issues are brought to the multidisciplinary team (MDT) for multidisciplinary decision-making and multi-agency solutions.
- Define timed care pathways, with proactive daily decision-making and clear escalation triggers.
- Ensure a team approach to care/discharge that is supported by protocol.
- Priority areas for improvement:
 - day case/23 hour breast surgery
 - laparoscopic colorectal surgery.

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7.6 Elective surgical patients and associated emergency readmissions

7.6.1 Key commissioning questions

- How many bed days can be saved if the trust or trusts in the network operate at the upper quartile performance for length of stay in key operations? How can bed capacity be released and savings reinvested elsewhere?
- Where can the greatest gains be made, by trust or by type of tumour? How can things be done differently?
- How can the length of stay be reduced?
- Can care be provided in alternative ways (for example moving from inpatient to day case to outpatient to home)?

7.6.2 Metrics

Benchmarked length of stay by specific procedures – by trust/network (provider) detailing:

- pre-operative bed days
- post-operative bed days
- bed days above HRG trim point and cost
- upper quartile performance calculation regarding potential bed savings.

Quality/efficiency indicators include:

- days in ITU/HDU
- readmission rates and complications.

7.6.3 Key actions

- Develop pre-admission clinics/systems.
- Ensure that diagnostic tests are completed prior to admission.
- Plan and ensure an integrated discharge package; refer early to other supportive agencies.
- Ensure that complex discharge issues are brought to the MDT for multidisciplinary decision-making and multi-agency solutions.
- Define timed care pathways, with proactive daily decision-making and clear escalation triggers.
- Ensure a team approach to care/discharge that is supported by protocol.
- Priority areas for change are to move to:
 - day case/23 hour breast surgery
 - laparoscopic colorectal surgery with enhanced recovery
 - open surgery with enhanced recovery in colorectal, gynaecological and urological (cystectomy and prostatectomy) services
 - same day admission for surgery.

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7.7 Elective oncology admissions

The three specialties of medical oncology, clinical oncology and haemato-oncology account for 25% of all cancer elective admissions.

7.7.1 Key commissioning questions

- Does the patient need to be treated as an inpatient? For example, can long infusions be given in the course of two separate visits to an ambulatory chemotherapy service?
- Can patients receiving radiotherapy use 'hostel beds'?
- Is the length of stay appropriate?
- What are the opportunities for community/ satellite services?
- Can opening hours of day units be extended?

7.7.2 Metrics

- Number of bed days under clinical/medical oncologists per 100,000 population in network of residence. (Note that this metric needs to be assessed together with overall bed usage in the network, as hospitals have different policies about admission to oncology or general medicine beds.)
- Benchmarked number of inpatient stays of two days or less, where chemotherapy is the purpose of admission, by trust/network of provision.

- Number of bed days where radiotherapy is the purpose of admission, by network (resident-based).
- Top 10 causes of admissions, benchmarked, for haematology and non-surgical activity.

7.7.3 Key actions

- Agree a list of regimens that can/should be given on an outpatient basis, and safe models of delivery.
- Develop models/exemplars for giving long infusions (chemotherapy and hydration therapy) on a daycare basis (e.g. bring patient in on consecutive days for infusions/hydration).
- Assess the potential for hostel accommodation.
- Give as much systemic therapy as possible on an outpatient/day basis assess impact through use of C-PORT.
- Introduce 'on-call oncologist' systems and daily ward rounds to ensure that there are no delays in discharging patients. (This can currently be a problem, as oncologists spend much of their time visiting other hospitals.)

More analysis will be undertaken on the top 10 causes of elective admissions as the Transforming Inpatient Care Programme rolls out.

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7.8 Reducing emergency admissions for patients with known cancer and treatment side effects

7.8.1 Key commissioning questions

- What is the annual increase in emergency admissions/bed days for my population?
- Can the adverse side effects of treatment be better controlled?
- Can the adverse side effects of treatment be recognised earlier and managed in an inpatient setting, reducing the need for patients to be managed in an ambulatory setting and preempting the need for emergency admission?
- Do patients have clear, agreed ways to re-access the services?
- Is appropriate, skilled support available from community/hospice services?
- Are patients being helped to make choices about where they wish to die? (Some 25% of emergency admissions end in death.)

7.8.2 Metrics

- Number of cancer emergency admissions per 100,000 unified weighted population. (Note that it is difficult to exclude undiagnosed patients from this metric.)
- Common causes of admission are:
 - febrile neutropenia/neutropenic sepsis
 - diarrhoea

- nausea/intractable vomiting
- anaemia
- pain
- retention of urine/haematuria
- shortness of breath/dvspnoea
- drainage of ascites.

7.8.3 Key actions for patients on active treatment

- Agree emergency symptom pathway.
- Develop protocols for supportive care, e.g. nutrition/granulocyte colony-stimulating factor to prevent side effects.
- Give comprehensive patient education to help patients/carers to recognise and manage symptoms.
- Give patients/professionals access to an emergency admission communication alert system/on-call oncologist.
- Monitor patients proactively (for example with telephone calls) for the early detection of problems.
- Manage side effects/problems on an ambulatory basis (e.g. bring patients into a chemotherapy suite for hydration/antibiotics).
- If admission is necessary, admit direct to an agreed location, i.e. avoiding accident and emergency (develop a policy about where assessment and treatment can be given and by whom).
- Where possible, don't admit: stabilise the patient and bring them back for treatment in an ambulatory setting.

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- Develop staff with generic oncology skills to support patient assessment.
- Develop an agreed emergency symptom pathway:
 - where should patients go?
 - who can treat patients?
- Define when a patient should be admitted and to where.

7.8.4. Key actions for patients with progressive diseases

- Set up a central, 24-hour emergency oncology clinical advisory service for GPs/accident and emergency/clinicians in district general hospitals.
- Establish systems for liaison with palliative care/ community matrons.
- Develop intermediate care services, recognised care homes and hospices.
- Establish good links with rehabilitation services and rapid access to equipment.
- Ensure that patient follow-up arrangements:
 - provide patient education on how to re-access services
 - promote self-management of symptoms and recognition of signs of disease progression.
- Help patients to think through their preferences and choices about their care, including where they wish to be cared for and die. (Some 25% of emergency admissions end in death.)

7.9 Emergency admissions for patients who are first diagnosed with cancer during their stay

7.9.1 Key commissioning issue

In a more engaged healthcare system, more people would be diagnosed through elective pathways. Cancers commonly presenting as emergencies are lung, colon, brain and acute leukaemias. Useful national data on routes to diagnosis is available in the NCIN 2010 Data Briefing: www.ncin.org.uk/publications/data_ briefings/routes_to_diagnosis.aspx

7.9.2 Metrics

• The number of emergency admissions without a known cancer but where the patient is diagnosed with cancer on that admission – per 100,000 unified weighted population, by SHA/ commissioner/network of residence (or by cancer incidence).

7.9.3 Key actions

- Develop an algorithm to support decision-making in accident and emergency or primary care.
- Set up an emergency communication alert system service for GPs/accident and emergency/clinicians in district general hospitals to enable rapid specialty assessment and arrangement of outpatient investigations.

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- Support GPs to stabilise patients at home and arrange to fast-track patients (i.e. quicker than two weeks) through an 'emergency rapid-access clinic'. (Put in place a policy for MDT co-ordination of this.)
- In the case of assessment in accident and emergency/surgical admissions unit/medical admissions unit, don't 'admit to assess' but rather 'assess the need to admit', through a well defined algorithm and with ready access to diagnostic tests. Either:
 - stabilise and discharge the patient, having booked tests for investigation on a planned pathway with navigation support
- or:
- if there is a need to admit, the decision should be taken by a senior consultant, with a management plan for the hospital ward to carry out, supported by a speciality oncologist on-call advice line and with a consultant visit within 24 hours, if required.
- Gain an understanding of the pre-emergency admission pathway.
- Have policies in place for the management of unknown primary tumours (NICE published final guidance on tumours of unknown primary origin in July 2010 – see: http://guidance.nice.org.uk/ CG104).

7.10 Commissioning to reduce inpatient admissions

This best practice document supports the proposed central themes of today's NHS commissioning and aims to provide for GP commissioning and support to networks and their trusts.

7.11 Who needs to be engaged in the inpatient/ ambulatory care management programme?

- 1. Cancer networks and commissioners, including practice-based commissioners, via:
 - the CCT and metrics
 - demonstration projects with NHS Improvement
 - discussions regarding contracts ensuring that an expectation regarding reduced admission is set out in explicit terms
 - setting up monitoring systems with operations directors in trusts
 - audits of appropriateness of emergency admissions/inpatient care
 - commissioning/contracting development programmes.
- 2. Oncologists, haematologists, clinical oncologists, medical oncologists, chest physicians and other medical specialties, who can:
 - develop treatment protocols for supportive care
 - establish 24-hour on-call advice lines

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- see all patients within 24 hours if admitted to any trust in the network
- develop models for ambulatory care
- consider oncology admission units at cancer centres to avoid accident and emergency.
- 3. Surgical oncologists, who can:
 - develop pre-admission systems, including discharge planning
 - develop inpatient care pathways
 - establish team-based, protocol-driven decision/ discharge systems.
- 4. Accident and emergency/medical admissions unit, which can:
 - develop algorithms to support assessment
 - ensure senior, swift decision-making by clinicians
 - stabilise and discharge if possible and put on the care pathway
 - ensure that management is in place before admission to a ward
 - throughout, ensure rigorous decision-making systems prior to admission.
- 5. General nurses, cancer nurses, chemotherapy staff, clinical nurse specialists, generic oncologists, who:
 - can provide a workforce that is available for longer opening hours, such as 8am–8pm

- have the skills and competencies to manage ambulatory care facilities, e.g. nurse practitionertype roles in medical oncology
- provide patient education
- ensure proactive management and telephone follow-up.
- 6. Allied health professionals, who provide, for example:
 - nutritional support/dietetics
 - rehabilitation for progressive disease/late effects.
- 7. GPs and community teams/facilities, who:
 - develop and support step-down facilities
 - provide 24-hour advice from oncologists/clinical nurse specialists
 - ensure protocols and system management
 - provide skilled community teams
 - work with specialist palliative care services to support palliative care in the community.
- 8. Specialist palliative care services, which:
 - use symptom management protocols
 - ensure best fit between location of care and complexity of care
 - agree criteria for admission and consistent thresholds for services.
- 9. Social workers

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7.12 Cancer Commissioning Toolkit metrics

The CCT contains the following metrics. The charts can be found by accessing the corresponding chapter **Inpatients – moving towards ambulatory care**.

7.12.1 Provider activity and efficiency

- Provider annual share of cancer bed days by cancer type
- Provider annual share of cancer bed days by trust
- Provider annual share of cancer bed days by specialty
- Provider share of daily occupied beds by cancer type
- Provider share of daily occupied beds by trust
- Provider share of daily occupied beds by specialty.

7.12.2 Inpatient activity by resident population

- Inpatient activity resident activity (FCE) per 100k unweighted population
- Inpatient activity resident activity (FCE) per 100k unified weighted population
- Inpatient activity resident activity (FCE) per 100k unified weighted population – trend analysis
- Inpatient activity resident bed days per 100k unweighted population

- Inpatient activity resident bed days per 100k unified weighted population
- Inpatient activity bed days per 100k unified weighted population – trend analysis
- Inpatient activity resident daily occupied beds per 100k unweighted population
- Inpatient activity resident daily occupied beds per 100k unified weighted population
- Inpatient activity resident daily occupied beds per 100k unified weighted population – trend analysis.

7.12.3 Provider activity and efficiency

- Enhanced Recovery Best Practice
- Transforming Inpatients
- NCAG Report www.ncat.nhs.uk/our-work/ensuringbetter-treatment/chemotherapy



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8. Living with and beyond cancer

8.1 Overview

Defining standards for improving patient experience in contract schedules for cancer and other patients is in its infancy within the NHS. However, NICE Supportive and Palliative Care (SPC) Guidance has helped to shape and formalise the agenda. Key recommendations of the guidance need to be included in service specifications and contract schedules covering the following areas:

- co-ordinated care within and across organisations with the patient being clear about whom to contact for support, especially out of hours
- high quality patient information to aid decisionmaking about treatment options and where treatment might take place
- effective face-to-face communications between professionals and patients
- individual, holistic patient needs assessment
- access to supportive and holistic services
- culturally sensitive service provision and availability
- routine data collection on patient experience across the patient pathway
- assessment on completion of treatment, supported by an individual plan for ongoing support and follow-up.

This best practice document is intended to begin the process of setting out some key principles in a number of areas which will require further development over time as data collection methods and datasets become more established, feeding standard quality indicators and measurement. The measures included should, therefore, be viewed as 'work in progress' to be developed and strengthened as schedules in contracts become more sophisticated and established practice within the commissioning process.

8.1.1 Information and improved patient experience – the challenge

The Government has set out a comprehensive programme of health reforms which includes a focus on patients having access to information that supports decision-making and choice of provider. The principle of 'No decision about me without me' (*Equity and Excellence: Liberating the NHS*, DH, 2010) is at the heart of putting control back into the hands of patients.

To ensure that patients are able to make informed choices and decisions about their care, they will require timely, tailored and high quality patient information.

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The National Cancer Patient Experience Survey 2004 identified that 40% of patients had not received printed information about their diagnosis, and 1 in 5 patients reported that they did not receive printed information on discharge. This figure improved in the 2010 National Cancer Patient Experience Survey, where 66% said that they were given information about their cancer type.

The 2010 National Cancer Patients Experience Survey has therefore shown some improvement in receiving information. However, wide variations can be seen at trust level across a number of information questions within the survey, with scores ranging between 29% and 90% for example, for patients receiving information about side effects.

8.2 Commissioning patient information services

The 2007 *Cancer Reform Strategy* paved the way for the creation of tumour-specific National Cancer Information Pathways. These pathways will provide commissioners with a basis from which to commission a minimum core set of patient information along a given pathway. To date, 44 tumour-specific National Cancer Information Pathways exist, covering over 87% of cancer incidence. The remaining pathways, including those for children and young people, were completed by April 2011. To support trusts to use these national pathways, a national support programme has been developed which incorporates the National Cancer Information Pathways into patient Information Prescriptions, which can be prescribed by healthcare professionals as well as accessed by patients themselves. (A national cancer Information Prescriptions implementation plan will be published shortly.)

The national support programme is currently being rolled out to support trusts across England to embed the principles and practice of providing patients with high quality, tailored patient information through Information Prescriptions. The support programme will run until July 2013, by which time all English trusts will have had the opportunity of a dedicated national facilitator to support the incorporation and embedding of Information Prescriptions across all cancer services.

The table below identifies key questions to support commissioners in identifying the infrastructural capacity of organisations to provide patients with tailored information that promotes decision-making and supports choice.

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Key commissioning questions for patient information services	Where to find the answers
Can the service provider demonstrate through audited records that at least 80% of patients receive information about their diagnosis?	Local provider reporting system until July 2013, then through NHS Choices Information Prescription Service
 Do patient records identify that information has been: (1) offered to patients? (2) accepted or declined? (3) dispensed by a named healthcare professional? 	Local provider reporting system until July 2013, then through NHS Choices Information Prescription Service
Is there a process in place that can identify the number of patients going through the trust who are eligible for an Information Prescription, and the number who actually receive or are offered a prescription?	Local provider reporting system Patient records
Is there an appropriate range of information available to patients within the cancer service? Can the provider demonstrate that a comprehensive range of information is available which covers the breadth of the National Cancer Information Pathway available at the key stages of the patient pathway (as demonstrated in the core national information pathways)? (For an up-to-date list of content on the pathways, log on to www.cancerinfo.nhs.uk)	Local provider reporting system until July 2013, then NHS Choices Information Prescription Service prescribing history after 2013

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Key commissioning questions for patient information services	Where to find the answers
Can the provider demonstrate through patient surveys that at least 80% of patients received information on discharge?	Patient surveys (national, local) NHS Choices prescribing history Patient records
Are staff involved in information delivery trained to assess patients' information needs and to provide a tailored Information Prescription at key stages of the patient journey? Is this recorded and a system in place to ensure that all new staff undertake the training?	Core team of staff trained on the nationally provided Information Prescription trainer course Local provider workforce action plan Local records of staff accessing the national training and support programme for cancer up to July 2013 E-learning tool/work book for Information Prescriptions incorporated into trust training programme records after July 2013
Is there a systematic process in place for assessing and recording the information needs of patients and ensuring that this is then recorded on the patient record?	Local provider reporting system until July 2013, then through NHS Choices Information Prescription Service Recorded on the holistic needs assessment
What arrangements are in place to ensure the smooth transition of patient information needs across the interface between secondary and primary care?	Trust patient information delivery strategy Trust implementation plans Network-wide information co-ordination plans

8.3 Supportive and palliative care

The 2004 NICE SPC Guidance was the starting point for raising the bar for the provision of supportive and palliative care for adult cancer patients. The guidance defines service models likely to ensure that patients with cancer, and their families and carers, receive support and care to help them cope with cancer and its treatment at all stages.

The guidance complements the series of Improving Outcomes Guidance (IOG) manuals on specific cancers. Although focused solely on services for adult patients with cancer and their families, the intention of the

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guidance is that it can inform the development of service models for other groups of patients. Unlike the other IOGs, the SPC Guidance relies on partnership working between the NHS, the voluntary sector and social care, and also cuts across primary, secondary and tertiary care.

The guidance provides a holistic and comprehensive guide to the development of supportive and palliative care services for patients, and their families and carers. This is in recognition of the fact that a diagnosis of cancer and its subsequent treatment can have a devastating impact on the quality of a person's life, as well as on the lives of their family and other carers.

In addition to receiving the best treatments, patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care. Most patients want detailed information about their condition, possible treatments and services. Good face-to-face communication is highly valued. Patients expect services to be of high quality and to be well co-ordinated. Should they need it, they expect to be offered optimal symptom control and psychological, social and spiritual support. They wish to be enabled to die in the place of their choice, often their own home. They want to be assured that their families and carers will receive support during their illness and, if they die, following bereavement. Since it was published in 2004, the principles of the guidance and key aspects of it have been reflected in the 2007 *Cancer Reform Strategy* (CRS); the 2008 *End of Life Care Strategy*; and the National Cancer Survivorship Initiative (NCSI) launched in 2008.

The Cancer Reform Strategy (DH, 2007) expanded the need for good supportive and palliative care for those patients living with and beyond cancer and for those requiring terminal care. It further reinforced the need for the implementation of the NICE guidance to significantly improve the quality of supportive and palliative care available to patients. It also put the focus on cancer patients and their families needing good psychological care and support, recommending that good psychological support services should be in place to support patients from the point of diagnosis and as they move along the patient pathway and progress their cancer journey.

The *End of Life Care Strategy* (DH, 2008) further reflected the need for good supportive and palliative care for patients nearing the end of life for all conditions. Specifically, it mirrored aspects of the SPC Guidance, such as co-ordination of care; assessment; communication; specialist palliative care services; advanced care planning; bereavement; and spiritual care. Unlike the implementation of the SPC Guidance, which is at the network level, the implementation of the *End of Life Care Strategy* is driven forward by strategic health authorities (SHAs) and primary care trusts (PCTs).

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Incorporating supportive and palliative care into other national initiatives and strategies has helped to keep the continued focus on the delivery of quality supportive and palliative care services to patients, and their families and carers.

8.4 Delivery of the agenda

Delivery can be defined by the following criteria:

- the requirement for local strategies to be developed and in place
- network leads to be appointed (rehabilitation; patient information and psychology)
- local service specifications to be developed
- ensuring that services are in place or developed and are in line with local need
- patients and their family/carers are aware that services are in place and are accessible
- good communication is practised between clinical teams
- training programmes are in place
- local audits are carried out to ensure the quality of the service.

8.4.1 Quality measures

To ensure the quality of good service provision for supportive and palliative care, national peer review measures are available for rehabilitation, advanced communication skills training, patient information, and key worker and holistic needs assessment. Furthermore, similar Quality Markers for End of Life Care* have been developed. Where measures are present and the networks are being reviewed, this acts as a lever for change in the system and facilitates 'buy-in' from key stakeholders. This has been the case, for instance, for rehabilitation provision, where networks are in the process of being peer reviewed, which has encouraged activity in this area. Specialist palliative care measures are currently being revised, but there has been a delay in issuing psychology measures. Networks have reported that this has had a negative impact on securing buy-in for the commissioning of services.

8.4.2 Implementation of the 2008 End of Life Care Strategy

The end of life care agenda has kept the focus on supportive and palliative care and also linked it into other long term conditions. The impact that this has on networks varies: some networks work with the end of life care lead (or sometimes the nurse director in that Home

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These are not NICE Quality Standards. NICE Quality Standard for end of life care is in hand.

role) to share the agenda and move things forward. Alternatively, it is seen by some as separate from the cancer networks and the timescales for implementation are different.

The *End of Life Care Strategy* is being taken forward in a number of ways, both nationally and locally. At the national level, the National End of Life Care Programme has developed a programme of work to support the implementation of the strategy.

The implementation of the End of Life Care Strategy alongside the implementation of the SPC Guidance has had an influence on the implementation of the guidance. Firstly, there has been national work taking place around assessment, communication, the development of the Views of Informal Carers - Evaluation of Services (VOICES) guestionnaire for bereaved relatives and competency development. Secondly, there has been some local work taking place, with all 10 SHAs committed to continuing the work that was started on end of life care as part of Lord Darzi's Next Stage Review.¹ A large number of PCTs had also identified end of life care as one of their top priorities, and end of life care has been adopted as one of the 12 Quality, Innovation, Productivity and Prevention (QIPP) workstreams. This has provided the opportunity for

networks to work with end of life care leads to move the agenda forward collaboratively.

Improving Outcomes: A strategy for cancer (IOSC) (January 2011) states that since 28% of all deaths are due to cancer, it is clear that many patients still require end of life care services and support.

The single national measure of progress on place of death is showing slow signs of improvement, with more people being enabled to die at home.

In order to incentivise investment in appropriate end of life care services, this work has been taken forward by an Independent Palliative Care Funding Review. This has made recommendations for a funding system that:

- covers care provided in all settings by hospices, the NHS or any other appropriate provider
- encourages more community-based care, so a patient can remain in their own home or care home
- will be fair and transparent to all organisations involved in palliative care

The review will report back by the summer of 2011.

1 Darzi, Lord (2008) High Quality Care for All: NHS Next Stage Review Final Report. London: Department of Health.

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There is a range of work in hand to improve the planning and co-ordination of care and to capture patient and carer experience. The national Dying Matters Coalition is also working to break the taboo on discussing death and dying. This currently inhibits both the public and professionals from having the key conversations which would permit proper care planning and understanding of patients' and carers' needs and wishes.

8.4.3 Performance indicators

The key metrics/performance indicators taken from the NICE SPC Guidance to assist commissioners in procuring appropriate levels of service for their population are as follows:

- Assessment and discussion of patients' needs for physical, social, spiritual and financial support should be undertaken at key points (such as at diagnosis, at commencement of treatment, during and at the end of treatment, at relapse and when death is approaching).
- All patients should be given a record of their consultation.
- Specialist palliative care advice should be available on a 24 hours a day, 7 days a week basis (see section 9: Commissioning end of life care).

- Medical and nursing services should be available for patients with advanced cancer on a 24 hours a day, 7 days a week basis (see section 9: Commissioning end of life care).
- Access to rehabilitation equipment should be made available within 24 hours of the patient requiring end of life care (see section 9: Commissioning end of life care).

8.5 Principles for commissioning services to support people living with and beyond cancer

As the number of people living with and beyond cancer increases, commissioners will want to ensure that effective care and support are in place which makes efficient use of health and care resources.

There are now about 1.8 million people living with and beyond cancer in England. The number of cancer survivors is increasing by over 3% a year. By 2030, there will be 3 million people in England who have had a diagnosis of cancer.²

Care after treatment for most cancer patients takes the form of regular outpatient follow-up appointments. Evidence from the NCSI suggests that a 'one size fits all'

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2 Based on Maddams J et al (2009) Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer 101: 541–547.

approach to follow-up does not meet all the medical, psychological, social, spiritual, financial and information needs that cancer survivors may have following their treatment, and does not provide value for money for the NHS.³

Investment in improved care pathways and better co-ordination of care for cancer survivors across service providers has the potential to deliver better health outcomes, better experience of care and cost savings, as unplanned healthcare use is reduced.⁴ Adopting improved care pathways can free up 'empty' outpatient appointments and enable investment in supportive care and specialist services for those who need them.

Emerging evidence from the NCSI suggests that commissioners should ensure that people living with and beyond cancer:

- have personalised risk stratification, holistic assessment and care planning at key points in the cancer pathway
- are supported to self-manage, where appropriate
- have access to case management support and/or specialist services, for example for the late effects of cancer treatment, or to assist with staying in or returning to work, where needed

- have access to appropriate information, including access to lifestyle advice and physical activity interventions
- are supported by planned and informed transition from paediatric to young person to adult services, where appropriate.

Commissioning improved cancer aftercare can enable organisations to deliver the five outcome domains described in *The NHS Outcomes Framework 2011/12* (December 2010). Improving Outcomes: A Strategy for Cancer describes improvements in outcomes that are relevant to people living with and beyond cancer, which include:

- reducing ill health associated with cancer treatment
- reducing the proportion of people who report unmet physical or psychological support needs following cancer treatment
- increasing the proportion of cancer survivors of working age and able to work who are in work
- increasing the proportion of children or young people survivors who are in education and employment
- increasing the proportion of cancer survivors who are able to live independently.

3 Department of Health and Macmillan Cancer Support (2010) *National Cancer Survivorship Initiative – Vision*. London: Department of Health.

4 NHS Improvement Adult Cancer Survivorship Initiative (2010) *Living With and Beyond Cancer: The improvement story so far.* Leicester: NHS Improvement; National Cancer Survivorship Initiative (2010) *Building the Evidence: Developing the winning principles for children and young people.* Leicester: NHS Improvement.

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Delivering improved care and support for cancer survivors will require commissioning risk stratified pathways of care across providers rather than commissioning episodic activities.

Models of care for many cancer survivors are generic with those for people with long term conditions. In some areas, specialist cancer-specific services and programmes are needed.

In line with the vision for improved joint working between the NHS and local authorities described in *Equity and Excellence: Liberating the NHS*, meeting the needs of cancer survivors will require improved integrated working between health and care services. Commissioners may wish to look to a joint commissioning approach where providers are able to tender for an integrated service covering health and care needs.

The principles for commissioners are described in more detail below.

8.5.1 Personalised risk stratification, holistic assessment and care planning are key to providing appropriate support for cancer survivors

Risk stratification takes account of needs associated with the disease, the treatment and the individual. Personalised care pathways based on risk stratification will mean that appropriate care and support are provided to meet individuals' needs. In common with long term conditions management, personalised risk stratification and assessment is likely to lead to:

- a small number of people with highly complex needs requiring intensive specialist management, for example for the effects of cancer treatment
- slightly more people needing a case management approach
- the majority of people able to be supported to self-manage.

Proportions will vary according to tumour type, and some survivors may not be able to take up self-management for social or psychological reasons, or because a case management pathway is more appropriate for those aged under 16.

Risk stratification enables better matching of services to individuals' needs and more efficient use of health and care resources.

People living with one or more long term condition, as well as those with cancer, should be offered a personalised care plan to support improved choice and control. Personalised care plans, developed in partnership between individuals and healthcare professionals, can empower people to manage their care and ensure that the full range of their needs is addressed. Evaluation of assessment and care planning

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for the NCSI suggests that cancer survivors value the care planning process and that their anxiety is reduced by it. 5

An end of treatment summary shared between cancer centres and primary care can improve survivorship care in the community. The treatment summary provides information about the cancer treatment given to an individual and supports the early detection, monitoring and management of the signs and symptoms of immediate or ongoing effects associated with the disease or its treatment. Following testing by the NCSI, 80% of GPs surveyed said they wished to continue to receive the treatment summary as they felt more informed about their patients' care, and 50% said that it improved their care of their patients.⁶

8.5.2 A risk stratified approach will mean that the majority of cancer survivors can be empowered to manage their own care through supported self-management

After the appropriate assessment, support and treatment, self-management may be appropriate for people who have a stable disease pattern and who have been treated with curative intent. Education programmes and information provision (such as that available through information pathways on NHS Choices) can enhance individuals' ability to exercise choice and control and build confidence to self-manage. Where people have the appropriate preparation and routes back into the system, self-management has been well received.⁷

8.5.3 Where supported self-management is inappropriate, cancer survivors may need access to case management support or specialist services

Following personalised risk stratification, assessment and care planning, some cancer survivors will require face-to-face monitoring or guided care. This may be appropriate for those who need to have a clinical examination, or who have co-morbidities, or for those with ongoing chronic disease. This approach is similar to a case management approach used to support people with long term conditions.

Some cancer survivors will need the support of specialist services to deal with the effects of the disease or its treatment – for example gastroenterological support for those treated with pelvic radiotherapy; speech therapy or dietician advice for those with head and neck cancers; support for lymphoedema; or vocational rehabilitation support for remaining in or transitioning back into work.

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5 www.ncsi.org.uk/wp-content/uploads/Assessment-and-Care-Planning-Workstream-Report.pdf

6 www.ncsi.org.uk/assessment-care-planning/treatment-summary/

7 Shepherd et al 2009, Implementing Recovery: A new framework for organisational change, Cancer Services Collaborative Improvement Partnership and Macmillan Cancer Support, February 2008.

8.5.4 Providing appropriate lifestyle advice and physical activity interventions can increase quality of life and are cost effective

There is a growing range of evidence that clearly demonstrates the close relationship between physical activity and:

- reduction in late and long term effects of treatment, including fatigue, cardiac and pulmonary function, bone health, muscle strength, weight and lymphoedema
- reduction in the incidence of relapse
- improvement in overall survival
- reduction in the risk of developing other co-morbidities, including coronary heart disease, hypertension, type 2 diabetes, chronic kidney disease and osteoporosis
- improvement in quality of life.⁸

There is also evidence that physical activity programmes for cancer patients are cost effective. Physical activity interventions such as group exercise referral programmes have been associated with reductions in hospital admissions and GP visits.⁹ Commissioning physical activity interventions is supported by the generic care pathway *Let's Get Moving*, which can be integrated into all long term condition management. *Let's Get Moving* can also be integrated into the Cancer Care Review in primary care.¹⁰

8.5.5 Planned and informed transition from paediatric to young person to adult services supports the continuity of quality of care for children and young people who are cancer survivors Planned and informed transition is essential to ensure the continuity of quality of care as children and young people transfer from paediatric to young person to adult services. This transition needs to be managed proactively. A planned approach in which information is provided at the right time from an experienced health professional who is known to the young person achieves a seamless transition to adult services. This also reduces the number who may be 'lost to follow-up' if transition arrangements are not planned and managed in advance.

8 Davies NJ, Thomas R and Batehup L (2010) Advising Cancer Survivors about Lifestyle: A selective review of the evidence. NCSI Lifestyle Evidence Review. Macmillan Cancer Support, Department of Health, NHS Improvement www.ncsi.org.uk/wp-content/uploads/Lifestyle-Review.pdf

9 Campbell et al (February 2007) 'Benefits of supervised group exercise programme for women being treated for early stage cancer: pragmatic randomised controlled trial' *BMJ* 334:517.

10 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_105945

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8.5.6 This new approach to aftercare requires appropriate care co-ordination systems, the development and implementation of robust remote monitoring systems for routine tests, and rapid access processes which enable access

to the appropriate team if there is suspicion of further disease

The NCSI is working to provide further evidence to support the commissioning of improved pathways that incorporate these features.

8.6 Key commissioning questions

Key commissioning questions for improved services for people living with and beyond cancer	Where to find the answers
What is the level of cancer prevalence in your area? What are the proportions in each tumour type?	Cancer network and PCT-level prevalence data on the National Cancer Intelligence Network website www.ncin.org.uk
What are the costs and activity levels for follow-up care arrangements in your area?	
What work is under way in your area to develop new models of care and support for cancer survivors?	NHS Improvement website: www.improvement.nhs.uk/cancer
Is aftercare for cancer survivors in your area informed by risk stratification, holistic assessment and care planning which focuses on the needs associated with the disease, the treatment and the individual?	
Are there opportunities to commission services for cancer survivors aligned with support for those with long term conditions?	
How do you measure the quality, effectiveness and safety of aftercare services in your area?	

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8.7 Cancer Commissioning Toolkit metrics

- Cancer deaths by place of death
- Cancer deaths by place of death, time trend
- Percentage of total cancer deaths by place of death.

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9. Commissioning end of life care

The *End of Life Care Strategy*, (DH, 2008) provides a blueprint for action, setting out the key priorities for improvement in end of life care. The strategy aims to improve care for people approaching the end of life whatever their diagnosis and wherever they are, including enabling more people to be cared for and die at home if they wish. It covers all adults in England with advanced, progressive illness, and care given in all settings.

Driving up the quality and availability of end of life care that is responsive to patients' needs and choices is a key role for commissioners. Commissioned services need to support:

- the identification of the end of life phase
- the need for timely conversations about end of life care
- assessment and care planning
- co-ordination of care
- review of care needs
- care in the last days of life
- care after death
- support and information for carers, including bereavement care.

Guidance and advice for people who commission end of life care services has been developed by the National End of Life Care Programme with its partners, including the Department of Health. This includes:

- examples of best practice from the UK and around the world
- links to relevant specialist websites
- guides, frameworks and policy documents as well as sample service specifications
- leaflets for members of the public.

This information can be found at: www.endoflifecareforadults.nhs.uk

The Government made a commitment to review payment systems to support end of life care, including exploring options for per-patient funding to meet the commitment in the Coalition Agreement. This work has been taken forward by an independent Palliative Care Funding Review. The review has made recommendations for a funding system that:

- covers care provided in all settings by hospices, the NHS or any other appropriate provider
- encourages more community-based care, so a patient can remain in their own home or care home
- will be fair and transparent to all organisations involved in palliative care.

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The recommendations will help to inform ministers on future spending and policy decisions on end of life and palliative care services. This will most likely include issues around the commissioning of end of life care services.

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10. Building for the future

10.1 Cancer research

Cancer care is more knowledge-based than any other branch of healthcare. Comprehensive evidence-based guidance on the organisation of services has been published by the National Institute for Health and Clinical Excellence (NICE) and significantly informs the relevant sections of this best practice document. A series of clinical guidelines continues to be published by NICE. An extensive range of technology appraisals is also available for cancer drug treatment. The search for new treatments continues, and the NHS has established a framework for the conduct of cancer research through the National Cancer Research Network (NCRN), which should have a close alignment with service delivery models in all networks.

The NCRN Co-ordinating Centre has set national targets for trial accrual and for randomised controlled trial accrual. In general, patients benefit – both directly and indirectly – from inclusion in trials, but the opportunity for patients to be included in trials is unevenly distributed across the country, with local as well as national variations. Patients have a right to access appropriate clinical trials, but their clinicians do not always facilitate this. Many research networks are dominated by oncology, and the service delivery model for chemotherapy dictates the accrual of patients. It is therefore sometimes difficult to map patient accrual into trials below network level. Research networks will routinely record the overall accrual of cancer patients into all studies and randomised trials in the National Cancer Research Institute (NCRI) portfolio. Commissioners should also enquire as to the locations where trials are open and the distribution of recruitment. In addition, they should enquire whether other (e.g. commercial) studies take precedence over NCRI studies in local portfolios.

Commissioners, working together at a cancer network level, should review the research performance of the network, taking into account the NCRI portfolio studies and other studies in their networks that are recruiting. They should seek a high level of recruitment, a broad portfolio of adopted studies (so that as many patients as possible have access to high quality studies) and equal access across the geographical area of the network.

Network boards should take a strategic view of the development of cancer research in their area, building links with relevant universities to ensure the continued growth of knowledge about cancer, its causes, the opportunities for prevention, natural history and the effectiveness of treatments.

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Print this page Print this section *Improving Outcomes: A strategy for cancer* (IOSC) highlights continuing and forthcoming research, including the following:

- The DH Policy Research Programme will provide funding from January 2011 for five years for a policy research unit on cancer awareness, screening and earlier diagnosis
- The Health and Safety Executive (HSE) has commissioned major research to explore further the potential association of shift work with breast cancer, other cancers and other major diseases. The HSE has also commissioned a number of research projects relating to asbestos
- DH has commissioned retrospective and prospective studies of young women with cervical cancer
- Continuation of randomised trial of the breast screening age extension, aiming for full roll-out in 2016
- Investigation of immunochemical FOBt
- ProtecT (Prostate testing for cancer and treatment) Trial
- UK Collaborative Trial of Ovarian Cancer Screening
- Lung cancer screening trial using spiral CT scanning
- Monitoring of international lung cancer screening trial results

- DH, with Cancer Research UK, to review findings of low dose aspirin study and consider appropriate advice to the public
- The Government will work with partners such as Cancer Research UK to support basic research into how cancer starts and develops; clinical and translateral research
- The National Cancer Equalities Initiative report set out several equality research priorities which are being discussed with the National Cancer Intelligence Network and the NCRI
- The National Institute for Health Research's NCRN is exploring inequalities in access to clinical trials and whether or not steps are needed to improve access in any patient group
- The NHS Cervical Screening Programme has commissioned researchers in Oxford and London to undertake a detailed study of the relationship between schizophrenia and bowel cancer
- The Pharmaceutical Oncology Initiative is commissioning research to explore the extent to which age is a factor in treatment decisions for a range of cancers.

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10.1.2 National clinical audit

There are currently four nationally designated clinical audits relating to different cancers:

- the National Lung Cancer Audit (LUCADA)
- the National Bowel Cancer Audit (NBOCAP)
- the National Head and Neck Cancer Audit (DAHNO)
- the Oesophago-gastric Cancer Audit.

National clinical audits for different cancers are helping to drive up service quality. The current audits will be maintained and we would expect new audits to be introduced over time. In the cancer field, an audit of prostate cancer is needed to stimulate improvements in quality and outcomes. We will ensure that there is no duplication of effort for the service in relation to cancer peer review.

Key commissioning questions for cancer research	Randomised controlled trials
What proportion of incident cancer cases is recruited onto NCRI portfolio studies?	Local NCRN
What proportion of cancer patients is recruited onto NCRI portfolio randomised trials?	Local NCRN
What is the distribution of patients recruited onto NCRI studies and randomised controlled trials, by NHS trust and PCT of residence?	Local NCRN
How do local (NHS trust and PCT) recruitment and network recruitment compare with national figures?	Local NCRN
Which trials are locally adopted, and why are any trials that are supported by the relevant multidisciplinary teams (MDTs) either not adopted locally or, if they have been adopted, not recruiting?	Local information from MDTs in the network site-specific group

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10.2 Ensuring a strong cancer workforce

10.2.1 General considerations

Commissioning of future cancer services should take account of the demand for certain skills. With advances in technology and new ways of working, it cannot be assumed that the current skill mix will be needed in the future. Short-term plans are limited by the current workforce in place, but medium- and long-term service plans are key drivers for workforce change. Therefore, commissioners and providers need to ensure that the skills required will be in place, through effective education and training, commissioning and appropriate continuing professional development opportunities for staff.

In addition, workforce supply and demand issues need to be underpinned by effective management of workforce change, with clear planning and effective engagement of key stakeholders across health and social care.

The consultation document *Liberating the NHS: Developing the healthcare workforce* (DH, 2010) sets out proposed changes to the workforce architecture and funding. Once the final recommendations are known, commissioners and providers of cancer services will have to be aware of who to engage with when developing service plans. Organisations such as the Centre for Workforce Intelligence and Skills for Health will continue to support health and social care, and are a good source of information and tools to support workforce development and planning.

10.2.2 Workforce plans

Commissioners should ensure that workforce plans contain the following considerations as a minimum:

- Workforce issues are addressed as an integral part of service planning. Workforce can be a constraint on how services are delivered, and issues need to be raised early enough in the planning process to enable alternative ways of delivering the services to be considered. This could include new providers and new workforces.
- Underpinning policy drivers have been considered, including the White Paper *Equity and Excellence: Liberating the NHS*, IOSC and DH outcomes and operating frameworks.
- External drivers have been considered, such as workforce demography, other labour market factors, including the demand from the independent sector, and the impact of technology/ legal changes.

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- Internal levers for change have been considered. These should be defined as concrete and measurable changes that have quantifiable outputs, including:
 - new ways of working skill mix, new roles, changed working practices
 - productivity gains through technology and process improvement
 - skills development enabling existing staff to take on enhanced roles
 - recruitment and retention initiatives e.g. new sources of recruitment and Improving Working Lives initiatives.
- The impact of change in service provision on other healthcare areas and pathways across organisational boundaries has been considered.
 For example, the shift in services from secondary to primary care may have the following effects:
 - Increased complexity of workload in secondary care as the easier cases are shifted to primary care. This may not result in a decrease in secondary care workload in proportion to the reduction in activity, but will require higher levels of skills.
 - Additional workload in primary care draws in staff from other areas of primary care or secondary care and will require additional education and training to equip staff for new roles.

10.2.3 Key cancer workforce considerations

Commissioners should consider the following:

- Better use of skill mix the appropriate transfer of tasks can free up the time of specialist staff who are in short supply, thereby helping to address critical skills shortages. The four-tier skill mix in therapeutic radiography is an example of this, where greater use needs to be made of assistant practitioner and advanced practitioner roles if the required increase in capacity of radiotherapy services is to be delivered.
- New training initiatives as a response to new technologies and NICE guidance, a training programme for laparoscopic surgery for colorectal cancer has been developed for surgeons and their teams, and commissioners should ensure that providers can offer the procedure to patients as an alternative to traditional surgery.
- New roles these can tap into new sources of supply and can sometimes address service delivery more effectively. They have included: the development of dosimetrists in radiotherapy; clinical nurse specialists improving the delivery of information, support and care to patients; and nurse endoscopists.
- **Better team working** well designed MDTs, where roles complement one another, will make the best use of skills and improve performance. Work has been undertaken to identify the characteristics of a high performing MDT.

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10.2.4 Cancer Commissioning Toolkit metrics

- Activity and cost by cancer type
- Activity and cost by trust
- Activity and cost by specialty.
- Total costs by cancer type
- Costs per FCE by cancer type
- Overview of cancer cost
- Costs per 100k unified weighted population.
- Excess bed days and costs by cancer type
- Excess bed days and costs by trust
- Excess bed days and costs by specialty
- Excess bed days by SHA/network/commissioning locality.

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11. Funding cancer services

11.1 Key issues

In total, an estimated £5.86 billion was spent on cancer services in 2009/10, amounting to £112.81 for every person in England and making cancer the third largest area of programme expenditure.

- Cancer drug costs have been growing at over £100 million per annum, and the *Cancer Reform Strategy* predicted that drug costs will continue to grow at a rate of approximately £60–80 million per annum. In 2008/09 spending on cancer drugs was over £1 billion.
- Cancer spend varies significantly across the country, with a two-fold variation in the spend per head of weighted population; but cost effectiveness and outcomes should be the key considerations when assessing the appropriateness of current investment levels in cancer services.
- Over 250,000 people in England are diagnosed with cancer every year and around 130,000 die from the disease. Currently, about 1.8 million people are living with and beyond a cancer diagnosis. Incidence is expected to increase and people are expected to live longer with cancer as new treatments become available. Therefore commissioners will need to respond to increasing demands on cancer services and spend.

• Improving Outcomes: A Strategy for Cancer (IOSC) was published on 12 January 2011. The strategy builds on the Calman-Hine report, *The NHS Cancer Plan* and the *Cancer Reform Strategy*. The Impact Assessment published alongside the strategy shows how an additional 5,000 lives every year can be saved by 2014/15 through early diagnosis and improved access to screening and radiotherapy.

11.2 Background

The outcomes articulated in IOSC will need to be realised within the context of the tighter financial environment ahead, with the ambition of achieving efficiency savings of up to £20 billion for reinvestment over the next four years.

In thinking about how best to deliver efficiency savings, commissioners will wish to note the three areas for potential savings highlighted in the National Audit Office (NAO) report *Delivering the Cancer Reform Strategy* (November 2010):

• use of radiotherapy machines varies over two-fold per year, per machine, by centre. While there may be valid reasons for these variations, the NAO identified potential for existing capacity to be used much more productively.

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- Inpatient admissions per new cancer diagnosis varied from 1.7 to 3.2 between PCTs in 2008/09. If all commissioners met the inpatient admissions per new cancer diagnosis of the best performing quartile, 532,000 bed days could be saved, equivalent to around £106 million each year.
- Average length of stay for inpatient cancer admissions varied from 5.1 to 10.1 days between PCTs in 2008/09. If every commissioner had the same length of stay as the average for PCTs in the best performing quartile, then even with no overall reduction in inpatient admissions, 566,000 bed days could be saved, equivalent to around £113 million each year.

For cancer care, there is good cost effectiveness data on NICE-approved cancer drugs and on some new procedures, but there is a lack of such data on radiotherapy regimens, palliative care and established surgical procedures. Maximum use should be made of available data to inform decisions in relation to cost effectiveness. Wherever possible, *Commissioning Cancer Services* seeks to identify the data that is available and that can assist in making such informed choices; where such data is not available, it offers some guiding principles.

11.3 Cancer – health investment

Programme budgeting data provides a breakdown of total spend, by commissioner, into 23 disease-based programmes. The Cancer and Tumours programme has the third highest spend, at £5.86 billion, after Mental Health and Circulation Problems. This constitutes almost 6% of total expenditure. Within Cancer and Tumours, the spend is broken down into ten sub-categories listed below.

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Cancer sub-programme	Total spend (£ billion)			
	2006/07	2007/08	2008/09	2009/10
Head and Neck	0.15	0.14	0.14	0.17
Upper GI	0.21	0.23	0.24	0.28
Lower GI	0.33	0.34	0.37	0.41
Lung	0.20	0.23	0.24	0.28
Skin	0.10	0.11	0.10	0.11
Breast	0.40	0.45	0.50	0.57
Gynaecological	0.16	0.16	0.16	0.18
Urological	0.41	0.43	0.44	0.46
Haematological	0.47	0.55	0.56	0.65
Other	1.93	2.32	2.39	2.75
Cancers and Tumours	4.35	4.96	5.13	5.86

Note: Figures may not sum due to rounding.

Programme budgeting provides a framework to enable commissioners to analyse comparative spend, health outcomes and the drivers of spend. With this broad understanding, local knowledge and interpretation should enable areas for extra investment and disinvestment to be deduced in an evidence-based way. The tools and guides to support this process are provided on the Health Investment Network website (www.networks.nhs.uk/nhs-networks/healthinvestment-network) and are briefly outlined below.

Currently, information is presented at PCT level, but development work is under way to ensure that this information can be presented at the level at which services will be commissioned in the future.

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11.3.1 Assessment of expenditure

Using the Programme Budgeting Benchmarking Tool, available in the 'Key Tools' section of the Health Investment Network website, it is possible to compare a commissioner's proportion of overall spend that is on cancer, and its sub-categories, with other commissioners and other diseases. It is possible to understand:

- how the commissioner spends its allocation over the 23 programmes and their respective subcategories
- how, and by how much, the expenditure distribution compares with that of commissioners nationally or locally, or with those that have similar characteristics
- how the expenditure distribution has changed over time.

A version of the tool is also available at cancer network level. This enables comparisons of cancer spend (including by site) across all the cancer networks in England.

Commissioners will need to review their spend against their priorities and the relative burden of cancer in their population in relation to other needs, for example if they have a population with a particularly high need for mental health services or if they have high birth rates and thus high maternity costs. Therefore, commissioners should also benchmark their spend in other programmes to identify any areas where they appear to be spending significantly more or significantly less than would be expected given their priorities derived from the needs of their population.

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11.3.2 Comparing spend with health outcomes

An assessment of relative spend is a useful starting point for health investment, but to understand whether the level of spend is appropriate it is important to look at other indicators of service quality and health outcomes.

The Association of Public Health Observatories has produced a useful tool to provide a high level comparison of spend and outcome, called the Spend and Outcome Tool (SPOT). This is available in the 'Key Tools' section of the Health Investment Network website: www.yhpho.org.uk/default.aspx?RID=49488. Information is available across all programmes, including cancer. The SPOT is very flexible and enables commissioners to identify those programmes that are potential outliers compared with other commissioning localities. Commissioners can use the tool to select the outcome measures they want to examine and which commissioning localities they want to compare with. By using the tool, commissioners will be able to identify:

- how the expenditure and outcomes compare with other commissioning localities nationally, within similar demographic areas, and against any other individual locality
- the relative expenditure and outcomes for the biggest spending programmes
- which programmes are significant enough outliers to warrant further, more detailed investigation.

The relative position of cancer can be assessed for each locality. Figure 11.1 below is an example of one of the outputs from the SPOT. The chart shows the relative spend (horizontal axis) and outcome (vertical axis) for one specific PCT compared with all other PCTs in England. Cancer is represented by a large diamond in the bottom right quadrant. The default outcome measure is mortality from all cancers (<75), but other measures can be selected. It would appear that, for this PCT, spend on cancer is relatively high and premature mortality is also relatively high. This could be worthy of further investigation.

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Figure 11.1: Example chart output from the Spend and Output Tool (SPOT)

E	arlier diagnosis
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	npatient care
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Relying solely on the SPOT to provide the rationale for investment and disinvestment is not recommended, however, as various studies have shown that there is no simple relationship between spend and outcomes. For example, a 1996 McKinsey report on healthcare productivity, which compared the US, Germany and the UK, found that higher spend does not mean better health outcomes. Health outcomes are affected by many factors, including lifestyle, timeliness of treatment and other factors that are not necessarily reflected in overall spend. In addition, inefficiencies can increase spend and decrease quality of services, so spend is increased but health outcomes are negatively affected. There is also a delay in seeing the benefits of some investments, for example on preventative work.

11.3.3 Identifying the drivers of cancer spend

Once spend and outcome have been assessed across programmes, the next step is to understand the drivers of spend. In the example above, the PCT appeared to have relatively high expenditure and high mortality rates for cancer. There are four main tools that can be used to understand the potential drivers of spend. All are accessible through the Health Investment Network website and are outlined below.

Programme Budgeting Atlases

The Programme Budgeting Atlases contain benchmarking data at PCT level to be displayed in a visual way. They enable the user to drill down to specific programmes and examine potential drivers of spend and health outcomes in much more detail. The atlases contain a range of information, including:

- rates of mortality and years of life lost for different types of cancer
- overall expenditure on cancer
- primary care prescribing expenditure on cancer
- hospital admission rates
- cancer prevalence and incidence
- screening rates
- deprivation.

The relationships between different datasets help to identify potential issues which can be explored further using a very useful scatter plot function. Figure 11.2 below is a sample map.

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Figure 11.2 Compendium of Clinical and Health Indicators/Clinical and Health Outcomes Knowledge



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NHS Comparators

NHS Comparators complements the Programme Budgeting Atlases, enabling the drivers of spend to be identified in more depth. This tool enables analysis at practice level and aggregation to emerging GP consortia level. It is a comprehensive benchmarking tool containing 200 indicators from primary and secondary care. The data is available quarterly and at SHA, PCT, GP practice and provider levels. Data is available for the cancer programme and by individual cancer site. By using NHS Comparators, commissioners will be able to identify:

- the drivers of spend in more detail, e.g. by looking at comparative emergency admission rates of similar organisations to see if they are higher or lower
- how key indicators have varied over time to see if levels of performance are consistent
- the balance between primary care and secondary care, e.g. if prescribing levels are relatively low or expected prevalence is lower than reported versus higher levels of emergency admissions.

Inpatient Variation Expenditure Tool

The Inpatient Variation Expenditure Tool (IVET) provides commissioners with a facility to examine whether

they are spending more or less on cancer inpatient admissions when compared with the national average. The standardisation is more sophisticated than that used in NHS Comparators because it allows for need as well as age and sex, using the practice-based Person Based Resource Allocation weighting.

Cancer Commissioning Toolkit

The Cancer Commissioning Toolkit is aimed at supporting the commissioning of cancer services across the NHS. It includes a range of high level indicators, as well as a number of links to more detailed information, right across the patient's journey: from prevention and screening through referral and treatment to living with and beyond cancer, as well as end of life care. A new addition is a set of GP practice profiles to support the new commissioning agenda.

Health Investment Packs

To illustrate the health investment process as outlined above, example packs are available for each PCT in England. These are available through the Health Investment Network website. About 30 of the packs featured cancer as an example programme to highlight the use of the tools. Useful examples are NHS Blackpool and NHS Tower Hamlets.

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11.3.5 Programme budgeting and marginal analysis

If a commissioner is a particularly high spender on cancer but still has poor outcomes, it needs to consider where money is currently being spent that could be redeployed, in evidence-based interventions, to achieve a greater health benefit for its population. Commissioners with relatively good health outcomes should consider if there is scope to improve them still further, either through more efficient use of the resources already being spent on cancer, or through additional investment.

To investigate this further, a reliable method is required to prioritise investments that deliver the greatest health benefits for patients. One such method is programme budgeting and marginal analysis. This stage requires a commissioner to analyse its spend and outcomes in detail, in light of local knowledge about its population and services. It is essential that a wide range of clinicians are involved in this process. Further details of programme budgeting and marginal analysis can be found on the Association of Public Health Observatories' website at: www.apho.org.uk Additionally, the following link provides an online video introducing programme budgeting and marginal analysis:

www.healthknowledge.org.uk/interactive-learning/pbma

11.3.6 Links to health investment resources

For further information about the health investment process, or any queries about using the tools, contact healthinvestment@dh.gsi.gov.uk. The following is a list of links to the key tools:

Health Investment Network www.networks.nhs.uk/nhs-networks/health-investmentnetwork

Programme Budgeting Benchmarking Tool, (including cancer network version) www.dh.gov.uk/en/Managingyourorganisation/ Financeandplanning/Programmebudgeting/DH_075743

Spend and Outcome Tool (SPOT) www.yhpho.org.uk/resource/view.aspx?RID=49488

Programme Budgeting Atlases www.healthknowledge.org.uk/interactive-learning/ pbma/chapter9

NHS Comparators www.nhscomparators.nhs.uk/NHSComparators/Login. aspx

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Inpatient Variation Expenditure Tool (IVET) www.networks.nhs.uk/nhs-networks/health-investmentnetwork/news/inpatient-variation-expenditure-tool-ivetupdated-1

Cancer Commissioning Toolkit www.cancertoolkit.co.uk/PublicPages/Login.aspx?AspxA utoDetectCookieSupport=1

11.4 Redistribution of funds within cancer spend

Within the overall envelope of spend on cancer, there may be opportunities to redistribute funds to achieve greater benefits for the money available. The following section provides some specific examples and identifies the evidence for investment and disinvestment at a national level; but commissioners need to evaluate their own data to identify where improvements can be made.

11.4.1 Inpatient care

Improving Outcomes: A Strategy for Cancer confirms the importance of focusing attention on inpatient care. Too many patients are being admitted into hospital and lengths of stay are often unnecessarily prolonged. NHS Improvement is leading a Transforming Inpatient Care Programme. This promotes:

day case/one night stay for breast surgery and other procedures

- enhanced recovery programmes for elective cancer surgery
- approaches to reduce avoidable emergency admissions
- reducing length of stay for those patients who do need to be admitted as emergencies.

The CCT includes a section within the 'Funding Cancer Care' module on 'Activity and Costs'. Here, commissioners can benchmark their activity by admission type, specialty and/or cancer site, and can identify the costs associated with this activity and the trusts in which the activity is undertaken. In this way, commissioners are able to identify any specific areas to target for potential efficiency gains.

Preventative and early detection interventions There is good evidence on the very favourable cost effectiveness of preventative interventions (such as Stop Smoking services and the breast, bowel and cervical screening programmes). Commissioners should ensure that they are maximising the potential reach of such interventions.

11.4.2 Drug spend

Drug spend is a key cost pressure, owing to the rate of increase of the cancer drugs budget as new drugs become available. Rather than look at overall spend, it may be more helpful to analyse the uptake of individual cancer drugs. Figure 11.3 below comes from

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a report on NICE-approved cancer drug usage for the National Cancer Director. The data shows variation in uptake of individual drugs from one cancer network to another. However, even with this level of information, interpretation remains difficult since such data is often difficult to fully adjust for need; and there is often no good objective measure of what the right level of provision should be.

Figure 11.3: Variation in uptake of NICE-approved drugs between cancer networks



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11.4.3 Radiotherapy

IOSC highlighted that access to radiotherapy is critical to improving outcomes. A modest increase has been made over the next Spending Review to ensure that full use can be made of existing radiotherapy capacity. Details can be found in the Impact Assessment which was published alongside IOSC.

11.4.4 Surgery

Surgery cures more patients of cancer than any other intervention, and has been the mainstay of treatment for many types of cancer over many years. Overall demand for cancer surgery is likely to rise, based on current trends, although the pattern does vary between cancer types.

As set out in IOSC, DH is taking action to ensure that the NHS delivers improved access to high quality surgery by:

- investigating incentives to ensure that clinicians are rapidly trained in new surgical techniques while continuing to fund any appropriate national training programmes centrally
- developing tariffs to incentivise the NHS to create appropriate training programmes quickly
- disseminating results from the National Cancer Equality Initiative's work on older people. This

will support the NHS in taking action to improve surgical intervention rates for older people who could benefit.

In addition, advice to commissioners and providers on robotic surgery for prostate cancer will be published in 2011.

11.4.5 Other areas

Commissioners need to make decisions based on a number of factors, and while ideally costs and benefits would be quantified to inform such decisions, in reality the necessary information may not be available. Therefore commissioners need to decide on the basis of a range of other information and lessons learned from other areas.

Figure 11.4 below (Things to do more of/less of) provides some possible areas for investment and disinvestment that commissioners may wish to consider in relation to funding cancer care.

11.5 Information sources

Commissioners should make as much use as possible of the information available to help them as they decide on resourcing levels. Programme budgeting data gives

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spend by condition and by cancer type, as was discussed earlier. NHS reference costs and Healthcare Resource Group (HRG) tariffs also provide key cost and activity data, which can be used to break down total spend into its constituent parts. This is covered further in Annex A.

11.6 Key questions for commissioners

- How much do you currently spend on cancer services?
- How is this distributed across the different cancer treatments and support services?
- Are you a relatively high or low spender on cancer services per 100,000 (unified weighted) population?
- Does this level of spend accurately reflect the level of priority that cancer should receive, relative to competing conditions and the various needs of the local population?

Figure 11.4: Possible areas for investment and disinvestment

- Do you have high rates of emergency admissions and readmissions?
- Are you a high user of inpatient bed days?
- How do your cancer outcomes compare with your relative spend? Are you a high spender and high achiever, low spender and low achiever; a low spender and high achiever (the ideal!) or (the worst case) a high spender and low achiever?
- Where could you invest to achieve maximum additional health benefits?
- Where could you disinvest without reducing benefits (for example, through the Transforming Inpatient Care Programme for cancer outlined in section 7: Inpatient care)?

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ings to do more of (= investment)	Things to do less of (= disinvestment)
 Better access to diagnostics where appropriate Screening and early diagnosis Alternative, more cost-effective places of delivery Smoking cessation and lifestyle interventions Targeting health inequalities Earlier NICE guidance on new interventions Supported discharge Poor asset productivity (e.g. linacs) 	 Unnecessary use of hospital beds Avoidable A&E admissions Nth line chemotherapy for patients with a poor prognosis Ineffective care Overuse of treatments near end of life Poor asset productivity (e.g. linacs)

11.7 Cancer Commissioning Toolkit metrics

The CCT contains the following related metrics. These can be found by accessing the corresponding chapter **Funding Cancer Care** and sections **Activity and Cost** and **Programme Budgeting**, either via the dashboard or content index.

Activity and cost

- Costs per finished consultant episode (FCE) by cancer type
- Activity and cost by cancer type
- Total cost by cancer type
- Activity (FCEs) per 100k unified weighted population
- Costs per 100k unified weighted population
- Normalised activity (FCEs) per 100k population trend analysis.

Programme budgeting

- Share of cancer spend trend
- Cancer spend breakdown by type
- Trend of actual cancer spend per 100k unified weighted population
- Benchmark of cancer spend per 100k unified weighted population.

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Annex A – A guide to undertaking an analysis of primary care trust spend

on cancer

Note – this Annex will be updated for the next version of the toolkit.

A1 Introduction

This annex seeks to help commissioners to analyse their spend on cancer, and hence to identify potential areas for more investment, for disinvestment and for efficiency improvements. There is a range of data sources available, and a number of options on how to go about analysing spend on cancer. This annex aims:

- to demonstrate a 'bottom-up' calculation of the spend on NHS cancer services by cost area in England (2005/06 estimate). This was undertaken by Department of Health analysts and published in the *Cancer Reform Strategy* (p. 119)
- to compare this estimate with programme budgeting data and clarify differences and agreements
- to consider how primary care trusts (PCTs) may replicate this analysis to obtain a breakdown of their own spend on cancer services.

A2 Key data sources

The 'bottom-up' calculation presented in this document uses the following key data sources for most of its cost estimates.

A2.1 Hospital Episode Statistics – admitted patient data

Hospital Episode Statistics (HES) provide detailed data on every patient admitted in England. For each episode of care, there is information available, such as diagnosis codes, procedure codes and length of stay. This allows us to identify cancer activity and, by linking with NHS reference costs, to estimate the costs associated with it.

A2.2 NHS reference costs

The National Schedule of Reference Costs 2005/06 for NHS trusts and PCTs combined gives details on how (and on what) over £36 billion of NHS expenditure was used in England in the 2005/06 financial year. It includes a breakdown of hospital admissions costs, outpatient costs, hospital radiotherapy and chemotherapy costs, and other primary and secondary care provision. Commissioners should have access to their local organisations' submissions to the national schedule, which they could use to obtain local activity and costs. Note that this document presents an estimate for 2005/06 costs, and that all the figures are in 2005/06 prices.

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A3 Bottom-up calculation of spend on cancer services in the NHS by cost area in England

Table A1 gives a summary of the cost estimates for England by cost area for 2005/06.

Table A1: Estimate of the costs of NHS cancer care in 2005/06

Cost element (2005/06)	Estimated cost (£m)
1 Primary care costs:	
1a GP visits for cancer diagnosis and treatment	104
1b Cancer screening programmes	225
1c Spend on cancer drugs prescribed in the primary care setting	211
2 Outpatient care costs:	
2a First and follow-up outpatient appointments relating to diagnosis of cancer	60
2b First and follow-up outpatient appointments relating to treatment of cancer	282
3 Hospital treatment costs:	
3a Hospital admissions with a primary diagnosis of cancer	2,415
3b Chemotherapy treatment costs	330
3c Radiotherapy treatment costs	205
3d A&E attendances for cancer patients	115
4 Other costs	
4a Specialist palliative care costs	200
4b Other costs	210
Total	4,357

The methodology and estimates used to derive this estimate follow.

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A4 Methodology and estimates

1a GP visits for cancer diagnosis and treatment

Data from the General Practitioner Weekly Returns database (Birmingham Research Unit, Weekly Returns Service, Annual Report 2003) suggests an estimated average of 619 visits related to neoplasms per 10,000 population per year. This equates to a cost of approximately £104 million per annum.

1b Cancer screening programmes

National figures suggest that £225 million is spent on breast and cervical cancer screening programmes annually (source: the DH). It is further estimated that, now fully rolled out, the bowel screening programme will cost £60 million per annum, so this can also be factored into future years' estimates.

1c Spend on cancer drugs prescribed in the primary care setting

Prescriptions and pharmacy statistics (PPS) enable us to break down NHS spend on cancer drugs in the community. The total cost of cancer drugs prescribed in the community has been estimated at £211 million (October 2005 to September 2006), the bulk of which (90%) goes on endocrine drugs.

2a First and follow-up outpatient appointments relating to diagnosis of cancer

NHS reference costs for 2005/06 provide activity and cost estimates for the following procedures performed in an outpatient setting:

- fine-needle biopsy of breast
- needle biopsy of prostate
- biopsy of cervix uteri
- rigid sigmoidoscopy
- colposcopy
- bronchoscopy
- diagnostic endoscopic examination of larynx
- diagnostic endoscopic examination of pharynx.

These totalled £60 million. (This assumes that all of these tests are attributable to cancer, as it is not possible from the data to distinguish the reason for diagnosis.) Although this is likely to be an overestimate, there will also be many other types of assessments for cancer (including, for example, MRI and CT scans) which have not been included here because the data is not available to distinguish the reason for diagnosis. While this figure may be inaccurate for these reasons, it is currently the best estimate possible based on the available data. Home

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cost estimates for the following outpatient specialties:clinical oncology

2b First and follow-up outpatient appointments

NHS reference costs for 2005/06 provide activity and

- medical oncology
- gynaecological oncology

relating to treatment of cancer

- radiotherapy (consultation only)
- chemotherapy (consultation only).

These totalled £203 million.

In addition, it was assumed that there are two outpatient appointments (i.e. one 'new' and one 'follow-up') for each cancer patient undergoing surgery. This can be confirmed by looking at HES data for elective admissions with a cancer diagnosis under a surgical specialty. This totalled £79 million. The total cost of all this activity was £282 million.

3a Hospital admissions with a primary diagnosis of cancer

HES 2005/06 data was used to identify cancer admissions as defined below, and was linked to NHS reference costs for 2005/06 to calculate the cost of this activity.

Definition of a cancer admission

We defined a cancer admission as one with an appropriate cancer diagnosis in any of the first three

diagnosis fields. An appropriate cancer diagnosis was any malignant, in-situ or uncertain neoplasm, or a benign tumour in a neurological site.

Linkage with NHS reference costs for 2005/06 The costs of the inpatient episodes were estimated using the NHS National Reference Cost Schedule 2005/06, which gives average cost figures for the country. Individual episodes recorded on HES have three key data fields, which are used to identify the correct cost of that episode: HRG, admission type and length of stay. A cost per episode can be identified, plus any additional costs for excess bed days. In addition, the Augmented Care Periods for bed days in intensive care or high dependency units can be identified and multiplied by the weighted average cost per bed day, also available within the NHS reference costs.

Further breakdown of admissions

In order to separate out the costs of surgery, it is possible to identify episodes in which a therapeutic procedure was undertaken. It is also possible to separate out admissions for chemotherapy, which may be identified using HRG codes ending in '98', e.g. C98 Chemotherapy with a Mouth, Head, Neck or Ear Primary Diagnosis. It is then possible to separate out the remaining admissions into day case and inpatient and elective and non-elective using the 'admission type' field. The results, in terms of total costs at a national level, are given below.

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Cost element	Cost £m	
Surgery treatment costs	628	
Day case chemotherapy (excl. drug costs)	139	
Inpatient chemotherapy (excl. drug costs)	135	
Other day cases	247	
Other elective inpatient costs	321	
Other non-elective inpatient costs	824	
Critical care costs	120	
Total	2,415	

Note: 2005/06 prices. Figures do not sum due to rounding.

3b Chemotherapy treatment costs

NHS reference costs for 2005/06 have a separate category for chemotherapy costs, which reflects just the drug component of costs, regardless of the setting in which it is administered (inpatient, day case or outpatient). This is separate from the costs within the inpatient or outpatient costs already outlined. In 2005/06 it was £330 million.

3c Radiotherapy treatment costs

NHS reference costs for 2005/06 have a separate category for radiotherapy costs, which reflects just the costs of the radiotherapy department, regardless of the

setting in which treatment is administered (inpatient, day case or outpatient). This is separate from the costs within the inpatient or outpatient costs already outlined. In 2005/06 it was £205 million.

3d A&E attendances for cancer patients

NHS reference costs for 2005/06 have A&E activity and costs, including for minor injury units, but this data is not broken down by diagnosis. It may therefore be assumed that cancer accounts for 9% of this activity, which is the proportion of overall emergency hospital admissions that is related to cancer (using the definition of a cancer diagnosis specified in 3a above). It equates to £115 million nationally.

4a Specialist palliative care costs

The National Council for Palliative Care estimates that the cost of specialist palliative care is in the region of £200 million for England. Some other estimates suggest a slightly higher figure, but as palliative care is not exclusively for cancer patients, the cost of specialist palliative care can be taken to be a reasonable estimate for the cancer element of the costs.

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4b Other costs

NHS reference costs for 2005/06 have a number of other categories of costs that will be incurred in relation to cancer. As a further breakdown of these costs by

patient diagnosis is not available, it is not possible to identify the cancer element of the costs, so the proportions need to be estimated. These are given in Table A2.

Table A2: Breakdown of 'other costs'

Element of 'other costs'	Percentage of costs due to cancer	Rationale
Community/outreach specialist nursing services, bands 1 and 2	95%	Bands 1 and 2 are 'Cancer' and 'Palliative/respite care'
Bone marrow transplant episode	94%	Percentage taken from British Society of Blood and Marrow Transplantation registry data 2006
Direct access: radiology services test	12%	Assumed to be in proportion to all admissions, of which cancer is 12%
Observation/pre-admission/medical admissions unit	9%	Assumed to be in proportion to all emergency admissions, of which cancer is 9%
Paramedic services provided by rural and urban teams	6%	Estimate is less than the 9% of emergency admissions that are for cancer because certain other conditions will be more time-critical than cancer

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Element of 'other costs'	Percentage of costs due to cancer	Rationale	
Community therapy services	3%	Low estimate for elements of costs	
Direct access: pathology services test	3%	where cancer is likely to take a low	
Rehabilitation services	3%	proportion	
Community nursing services	3%		

These totalled £210 million nationally.

A5 Comparison with programme budgeting data

The National Programme Budget (PB) project provides a retrospective appraisal of NHS resources, broken down into programmes. One programme is Cancer and Tumours. The total figures agree well with the bottom-up estimate outlined in this document (for 2005/06 the figure was £4,302 million, so it was within 1% agreement), but there are key differences in what is included in each analysis of spend, and these render the comparison not 'like for like'.

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A6 How to undertake PCT estimates

Factors excluded from PB data but included in bottom-up estimate	Factors included in PB data but excluded from bottom-up estimate
GP visits In PB data, these are included in the programme General Medical Services/Personal Medical Services	Benign tumours excl. neurological ones PB data includes benign tumours, which in particular will attract significant costs in hospital inpatient activity
Cancer screening programmes In PB data, these are included in the programme Healthy Individuals	Possible areas not identified in the bottom-up estimate include: imaging activity, outpatient activity relating to diagnosis of cancer not in oncology specialties, genera palliative care
Admissions with a secondary diagnosis of cancer but a non-cancer primary diagnosis These may be counted against a number of PB categories for other conditions	

Commissioners may wish to undertake a similar analysis of the breakdown of cancer spend in their own area. The methodology presented here for creating a national estimate can generally be replicated at a local level, using local information, to reflect the local spend. It is also possible to short-cut some of this work using tools that are available and alternative estimates of some cost elements. There is more detail on this below.

A6.1 Local data

NHS reference costs returns are available by organisation, so a commissioner can use the returns from the main acute trusts, as well as its own return. It can also use the organisations' Patient Administration System (PAS) data to identify the admitted patient activity. These two information sources will allow a commissioner to estimate most of the cost elements.

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A6.2 Tools and alternative sources

The Cancer Commissioning Toolkit provides cost estimates for inpatient activity by PCT and cancer network, according to the definitions and methodology provided here.

The National Programme Budget data will provide an estimate of total spend on cancer, and of this, the amount spent on cancer drugs. This estimate of spend on cancer drugs is a helpful alternative source for the costs of chemotherapy and primary care cancer drugs in this annex. However, it may not agree exactly with the estimates in this annex, as the sources differ. The estimate of total spend on cancer is a helpful benchmark for commissioners and is included in the Cancer Commissioning Toolkit, but the differences in definition described above should be noted.

A6.3 Remaining areas

There are some areas for which a local estimate of spend will not be possible based on these sources, particularly general practice costs. Commissioners will need to use other data available to them in order to create a locally adjusted estimate of this cost.

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