

Improving Outcomes: A Strategy for Cancer

First Annual Report 2011



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Foreword

It is slightly less than a year since we published *Improving Outcomes: A Strategy for Cancer*, but we felt that it was important to get the first annual report out in time for the Britain Against Cancer conference. Traditionally this is an occasion when we reflect on and discuss achievements over the past year and the challenges ahead. We hope that this report will inform this discussion.

This is only the first annual report on the new Strategy, so it is not surprising that there are still many challenges in terms of achieving the quality of cancer services and outcomes that the Strategy set out to deliver. But progress has been made, both in terms of developing the new structures which will deliver the improved outcomes and in terms of immediate achievements.

The Government's focus on outcomes has been widely welcomed by those involved in cancer service delivery. The Public Health Outcomes Framework will be directly relevant to the prevention and early diagnosis of cancer and all five domains of the NHS Outcomes Framework are relevant to cancer patients – reducing premature mortality, improving quality of life, enhancing recovery, improving patients' experience of care and improving safety. We have therefore structured this report around these outcomes.

Most importantly, the Strategy set out an ambition to save 5,000 additional lives per year by 2014/15. A great deal of work is now underway to achieve this and to define how progress can best be monitored both nationally and locally.

In terms of immediate achievements, we would like to highlight just a few that are important in terms of delivering improved outcomes:

- there have been further improvements in data and analyses that we have to support clinicians, commissioners and providers to improve services and patients to make informed choices about services. For example, detailed analysis of the 2010 cancer patient experience survey has enabled the NHS to take action locally on areas where they have performed less well; we are starting to have good data about the needs and quality of life of the 1.8 million cancer survivors in England, which will help the NHS plan and provide the right services
- we are continuing to extend the age range for bowel and breast cancer screening and are moving forward with the work to introduce a flexible sigmoidoscopy bowel screening programme

- we have successfully run a range of campaigns to improve the public's awareness of cancer symptoms and to encourage them to present promptly to the doctor. It will take time to bring about significant change in behaviour, but we believe that we have started the move that is necessary for us to deliver earlier diagnosis of cancer
- surgical training programmes on laparoscopic colorectal cancer and low rectal cancer are helping to improve the quality of surgery for patients and to promote earlier recovery
- the NHS has continued to improve care pathways in order to reduce inpatient bed days – reducing costs and improving the quality of care for patients.

Whether by improving quality of life or giving patients precious extra time with their loved ones, access to clinically effective cancer drugs can make a real difference to individual patients and their families. Over the past year we have seen the impact of the introduction of the Cancer Drugs Fund, building on the additional funding the Government made available to the NHS in 2010 to give patients better access to cancer drugs that would not otherwise be available from the NHS. The £600 million Cancer Drugs Fund has been widely welcomed for the freedom it is giving clinicians to prescribe the cancer drugs they think are best for their patients and for the positive impact this is having on the lives of individual cancer patients. Since October 2010, over 7,500 patients have accessed additional cancer drugs as a result of the funding we have made available and many thousands more will benefit over the life of the Cancer Drugs Fund. The information generated through the Cancer Drugs Fund also provides an unprecedented opportunity to assess the benefits that these drugs deliver in real-world clinical practice, and to build the evidence base for the future.

In terms of the priorities for the year ahead, we need to continue to support the NHS to:

- deliver improved cancer survival rates, with a particular focus on:
 - moving forward on piloting flexible sigmoidoscopy bowel screening
 - continuing with the age extensions to the breast and bowel screening programmes
 - supporting the NHS to achieve earlier diagnosis of symptomatic cancers through campaigns to raise awareness of symptoms
 - improving diagnostic capacity and productivity, especially for lower GI endoscopy (eg colonoscopy)
 - improving access to appropriate treatment – for example, through providing information about variations in intervention rates

- improve the quality of life of cancer survivors, in particular through promoting:
 - a better understanding of the numbers of survivors in different phases of the post primary treatment pathway
 - the needs of survivors in those different phases
 - optimal treatments to minimise long-term side effects
 - the care and support which enables survivors to live as healthy a lifestyle as possible, for as long as possible
- improve patient experience, primarily through:
 - providing information to commissioners and providers about patients' experience of care and bereaved families' and carers' views about end of life care, so that they can identify the areas where improvements are needed
 - giving support to tackle the issues identified, eg around information provision and better communication.

There are of course many other individual actions that we need to focus on, not least moving forward on the establishment of a proton beam therapy service. We are now fast tracking the next phase of this project so that we will know what a national service may look like in terms of the numbers and location of facilities by the end of March 2012.

The Operating Framework for next year has made it clear that NHS organisations should continue to work to implement the Strategy and at national level we will continue to provide the support required.

We would like to take the opportunity to thank all the patients, clinicians, managers, charity representatives and other stakeholders who have contributed to our work at national level over the course of the year – and to all those across the NHS who are providing the best possible care and support to cancer patients.



Rt Hon Andrew Lansley CBE MP
Secretary of State for Health



Paul Burstow MP
Minister of State for Care Services

1 Focus on Information Revolution

Introduction

- 1.1 As we said in *Improving Outcomes: A Strategy for Cancer* (IOSC), information is central to the drive for better outcomes. This chapter reports on progress in collecting better information and on analysing and using it more effectively and on our priorities for the coming year.
- 1.2 In taking forward our work to improve intelligence, we have focussed on the commitments set out in IOSC, the criticisms made by the Public Accounts Committee (PAC) in its report *Delivering the Cancer Reform Strategy*¹ in February 2011 and the need to support the new developing organisations and their priorities. As promised in the Treasury Minute responding to the PAC report, we are planning to publish a document, a *Cancer Intelligence Framework*, summarising what cancer intelligence is available now, what new data and analyses will be coming on stream and when (subject to the appropriate Review of Central Returns (ROCR) and the Information Standards Board (ISB) approvals prior to commencement) and our aspirations for the future.
- 1.3 Going forward, our work on the *Cancer Intelligence Framework* should be seen in the context of this Government's broader proposals for better use of information, more openness, transparency and comparability. The White Paper consultation *Liberating the NHS: An Information Revolution* closed earlier this year. A summary of responses to the consultation giving views on the way information is controlled, accessed, collected, analysed and used by the NHS and adult social care services – so that people are at the heart of these services – was published in August 2011². Following further anticipated input from the NHS Future Forum, work to develop the subsequent Information Strategy for health and social care in England is ongoing, aiming to publish by April 2012. The immediate actions to improve cancer intelligence, set out below, are broadly in line with the

1 Public Accounts Committee – *Twenty-Fourth Report: Delivering the Cancer Reform Strategy* (February 2011)

www.publications.parliament.uk/pa/cm201011/cmselect/cmpubacc/667/66702.htm

2 *An Information Revolution: summary of responses to the consultation*, DH, August 2011
www.dh.gov.uk/health/2011/08/information-responses/

Information Revolution proposals. Longer term work will be set within the broader strategic plans to follow in the forthcoming Information Strategy.

Collecting better information

Diagnostic imaging

- 1.4 Work is well underway to develop a new system for collecting detailed data on NHS diagnostic imaging test activity. The DH is currently seeking approval from ROCR and the ISB, with a decision due in January 2012, to collect these data which are required to enable commissioners and GPs to assess their usage of diagnostic tests, as part of the move to encourage prompt investigation of symptoms which could be cancer.
- 1.5 With the aim of improving patient care, from April 2012 the DH has proposed that providers of NHS funded diagnostic imaging services extract data from local Radiology Information Systems (RISs) and upload them to a central system, which will be managed by the NHS Information Centre (the IC). These data will enable detailed analysis of variation in activity and waiting times, including benchmarking of GPs' direct access to particular diagnostic tests. The collection will also serve a number of broader purposes, such as extending data on pathways for registered cancer patients and providing the Health Protection Agency (HPA) with detailed data to inform their reporting on the frequency and dose for medical x-ray examinations.
- 1.6 An Information Standard Notice is scheduled for publication in January 2012, with data reporting commencing from April 2012. In line with other transparency commitments, the IC will make data available to support publication via a number of routes, including web-based statistical publications and new indicators in the National Cancer Intelligence Network's (NCIN) GP practice profiles. The data will also be published in processable formats to enable further information "intermediaries" to carry out further analyses or present this data in innovative ways that are useful for specific audiences.

Radiotherapy

- 1.7 The first annual report on the radiotherapy data set (RTDS) for 2009/10 was published in July 2011. This gives us, for the first time, an accurate baseline from which we can measure and assess improvements and changes in radiotherapy services and support a review of the National Radiotherapy Advisory Group (NRAG) metrics.

- 1.8 The radiotherapy data collection shows that there were approximately 31,000 attendances for radiotherapy per million head of population per annum in 2009/10. This equates to approximately 34,500 fractions (the NRAG report in 2007 recommended 40,000 by 2010/11). The data collection also suggests that NRAG had overestimated the number of fractions delivered at that time so the baseline was in fact lower than 30,000 per million per annum.
- 1.9 Analysis by cancer network shows that access to radiotherapy does not vary as widely as previously thought once local demographics are accounted for. However, variations between networks persist and low uptake in northern networks cannot be explained by variations in cancer incidence. There is more variation in the uptake of radiotherapy for prostate cancer than there is for radiotherapy for breast cancer, and greater variation in uptake of palliative radiotherapy than radical radiotherapy.
- 1.10 We can now focus on understanding the reasons for variations in provider activity. A detailed modelling tool – *Malthus* – was launched at the NRAG conference in November 2011. It allows commissioners to consider the volumes of radiotherapy they should be commissioning for their populations, the sites they need to focus on to improve access and whether local oncologists are prescribing radiotherapy within nationally agreed best practice.
- 1.11 *Malthus* has modelled demand using more detailed information than that available at the time of the NRAG report and taking account of changes in practice over the last five years. While *Malthus* generates an estimate of radiotherapy demand at a national level, it is clear that this demand is more appropriately expressed as a local figure. The *Malthus* national demand figure is lower than the NRAG estimate but, importantly, it identifies variation in demand at a local level. Additionally, *Malthus* has the ability to model changes in demand as the change in access (from 38% to 52%) is seen at different times in each area. It is still expected that this increase in access will occur, but the timelines are less clear. To continue to meet increasing demand and waiting time requirements, local services are encouraged to plan for this rise in access. Additionally, services should continue to plan for a 13% greater capacity, as recommended in the NRAG report.
- 1.12 The 2009/10 data also showed 6,660 fractions per linac in regular use. NRAG had recommended 8,300 by 2010/11. There are a number of

factors which affect fractions delivered per linac. Locally, commissioners and providers will agree an appropriate balance between access and productivity. Fractions per linac should be seen as a measure of capacity as opposed to a measure of productivity. The National Radiotherapy Implementation Group (NRIG) is addressing productivity by developing a tool to demonstrate “the productive radiotherapy service”. It is also commissioning a survey of patients’ appointment time preferences to inform work around opening hours.

- 1.13 The RTDS provides data about the proportion of fractions delivered through intensity modulated radiation therapy (IMRT). This is very important in informing our efforts to improve the spread of IMRT – see chapter 4.
- 1.14 The RTDS annual report for 2010/11 is already in preparation and, building from the previous year’s report, will focus on equalities when published in early 2012.

Chemotherapy

- 1.15 Work remains on track for the chemotherapy dataset collection to be mandatory for NHS Trusts and voluntary for NHS Foundation Trusts with a phased collection beginning in April 2012. Findings from the pilot sites were very encouraging and we have been working with Trusts to raise awareness and make links to facilitate the start of the collection.

Improving the cancer registration process

Review of cancer registration

- 1.16 In 2010 the reliability of cancer survival data for England was questioned by two leading cancer epidemiologists. In response to this, the DH and Cancer Research UK instituted a comprehensive review of cancer registration.
- 1.17 In summary this work has shown that:
- some cases of cancer are missed – these include cancers with both good and poor prognoses
 - there is a lack of standardisation of the sources of information used by cancer registries to ascertain new cases (eg pathology systems, clinical management systems, waiting times databases, patient administration systems etc)

- there is overreliance on death certification and retrospective tracing of date of diagnosis
 - only a minority of all cancer patients have information on stage of disease on the diagnosis record – this hampers evaluation of efforts to drive earlier diagnosis and also limits case mix adjustment for comparisons of survival.
- 1.18 However, phase one of the work concluded that deficiencies in cancer registration do not explain the differences in survival rates that have been observed between England and other comparable countries. A final report should be ready in spring 2012.

Timeliness

- 1.19 All cancer registries have made significant improvements to their overall timeliness. All registries met the shortened timeliness target for 2009 cancer registrations, completing by the end of March 2011 (15 months after the end of the year, from the previous requirement of 18 months).
- 1.20 One registry completed their 2010 registrations by the end of August 2011 (8 months). All other registries are on target to hit the further shortened 12 month deadline for 2010 data, such that the 2010 registrations will be complete by the end of 2011.

Modernisation

- 1.21 The cancer registries in England are currently engaged in a modernisation programme which will see all existing registries migrate to a single processing system, the English National Cancer Online Registration Environment (ENCORE), by the end of 2012.
- 1.22 When all registries have migrated to ENCORE, a whole tier of replicated data processing and cost will be removed, with significant additional benefits in terms of timeliness, quality and increased use of relevant clinical information. To illustrate this, and as reported by the NAO, NCIN funded an investigation into the potential benefits of converging the IT systems of two cancer registries in 2009. This convergence led to improvements in data quality and savings of £88,000 through reductions in IT costs and improvements in the efficiency of data preparation, validation and processing. Savings are therefore likely to be greater across the other registries.

- 1.23 Feedback systems on data quality, accuracy and completeness are integral to the ENCORE model and will allow clinical teams to compare their own data quality (at a field level, if required).

Staging

- 1.24 Under the guidance and monitoring of a new National Staging Panel, all cancer registries are now implementing internal changes to achieve the staging performance of the best registry. This aim is that for the 80% of cancers which are considered to be "stageable", 90% will have stage recorded, ie 70% of cancers are to be staged. Registries are on track to deliver this by the end of 2012.

Metastatic breast cancer collection

- 1.25 IOSC outlined the requirement for a better understanding of the prevalence and management of patients with recurrent and metastatic breast cancer. We know that almost half a million women are living with and beyond a diagnosis of breast cancer, but do not know what proportion of these have advanced disease. Without this information, it is impossible effectively to plan the services these patients need. NCIN, in collaboration with Breast Cancer Care and 15 breast multi-disciplinary teams (MDTs), are currently piloting the collection of data on recurrence/metastases for patients with breast cancer with the aim of undertaking a full collection from April 2012 across all MDTs in England. Further information on the data to be collected and the processes for submission will be shared with all MDTs and breast services over the coming months. The collection of these data is expected to be managed via existing information flows, including cancer waiting times and routine MDT extracts to cancer registries.

Analysing and using data more effectively

Data on cancers diagnosed via emergency routes

- 1.26 The NCIN is undertaking an extension of the original *Routes to Diagnosis* report. This new analysis will cover three years of cases, allowing trends in the types and levels of routes to presentation to be understood and addressed. We are also exploring how rapidly available national data sources can be used to monitor changes in emergency presentations in a much more timely manner. This is not a new data collection, but a project to link and analyse existing data sets (Hospital Episode Statistics – HES, cancer waiting times and cancer registries).

Profiles

- 1.27 Using existing data collections, NCIN and the National Cancer Action Team have developed Trust level service profiles for breast and colorectal cancer MDTs as part of the proposed support for cancer commissioning. These were shared with local MDTs during November for a period of consultation and comment, and will be available to the wider NHS from mid-December through the Cancer Commissioning Toolkit.
- 1.28 The profiles contain benchmarked information relating to over 30 metrics or indicators from multiple data sources such as cancer waits, HES, peer review, cancer registration and the national cancer patient experience survey, in one easy to understand format. Profiles for other cancer areas will also be developed in line with service specifications currently being prepared by commissioning groups.
- 1.29 The GP practice profiles for cancer, first published in December 2010, will also be updated for the end of 2011. These have proved to be very useful both to commissioners and to GP practices themselves.

International Cancer Benchmarking Partnership (ICBP³)

- 1.30 The first findings of the ICBP, published in *The Lancet*⁴ in January 2011, suggested that English survival rates continue to lag behind the best performing countries in the partnership and that, with the exception of breast cancer, we are not narrowing the “survival gap” to move closer to the best performing countries. An analysis has been undertaken on the impact stage and treatment have on survival rates for each cancer within the study. The analysis on stage is due to be submitted to a peer-reviewed journal in early 2012, with the analysis on treatment shortly after. The partnership has also submitted a paper for publication on the groundbreaking methodology developed for reconciling cancer registry stage data for international analysis, which has been submitted for publication and should be available in early 2012.
- 1.31 Survey fieldwork has been completed across all ICBP jurisdictions in order to provide the first robust international comparison of population awareness and beliefs in relation to cancer. This will allow us to explore the role played in cancer survival by these levels of awareness and beliefs

3 www.icbp.org.uk

4 Coleman et al, *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*, Volume 377, Issue 9760, Pages 127 – 138, 8 January 2011

and will identify where interventions to address low cancer awareness and negative beliefs should be targeted. International comparisons are due to be published in spring 2012.

1.32 Other priorities for the partnership include:

- a study of beliefs, behaviours and systems in primary care, for which an international survey of GPs will be undertaken in early 2012
- a study of the root cause of diagnosis and treatment delays, for which an English pilot is planned for early 2012, with international pilots and fieldwork following later in the year.

National clinical audit

1.33 Following an open invitation to professionals working in all areas of health care to propose new topics for the National Clinical Audit and Patient Outcomes Programme, eleven proposals were selected by the DH, including a prostate cancer audit which will be commissioned in 2011/12 and a breast cancer audit which it is anticipated will be commissioned in 2012/13.

Analysing and using data by equality group

1.34 As set out in the NCIN Work Programme 2011/12 supplement, the NCIN has done more work on equality issues than any other area. Reports to date include: a summary of evidence on inequalities as a baseline for the National Cancer Equality Initiative (NCEI) report *Reducing cancer inequality: evidence, progress and making it happen*⁵; reports on cancer incidence and survival by major ethnic group, cancer incidence by deprivation and the excess burden of cancer in men in the UK; data briefings on breast cancer and deprivation, breast cancer in older people and breast cancer and ethnicity; and the electronic toolkit Cancer Equality Portal (www.ncin.org.uk/equalities). All the reports can be viewed on the NCIN website: www.ncin.org.uk.

1.35 Wherever possible, all NCIN reports are published broken down by equality characteristic. All new datasets include gender, socio-economic deprivation and age (including older people and children, teenagers and young adults). The estimate of ethnicity code completion at cancer registries is now 85%. Sexual orientation, disability and religion cannot be

5 *Reducing cancer inequality: evidence, progress and making it happen – A report by the National Cancer Equality Initiative (March 2010)*
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114354.pdf

included as they are not routinely recorded in acute care. However, the new cancer registry system design allows it to be extensible, and will allow such data to be received centrally and analysed. The NCEI are looking to pilot this with local teams.

- 1.36 The IOSC Assessment of Impact on Equalities (AIE)⁶ was published alongside the Strategy in January 2011. Ongoing work to promote equality and reduce health inequalities is central to the Strategy and it is set out throughout the chapters of this annual report. An update will be considered for the second annual report once more of the actions promoting equality and reducing inequalities have come to fruition.

Analyses published during 2011

- 1.37 The table shows the wide range of analyses published by NCIN over the last year:

Table 1.1. NCIN Publications 2011

Document type	Title	Publication date
Data briefing	Cervical cancer incidence and screening coverage	January 2011
Report	Profile of cervical cancer in England	January 2011
Data briefing	Is pancreatic cancer becoming more common in the young?	January 2011
Data briefing	Soft tissue sarcomas: incidence and survival rates in England	February 2011
Data briefing	Central nervous system (CNS) tumours – developing a national tumour registry	March 2011
Report	NHS treated cancer patients receiving major surgical resections	March 2011
Data briefing	Screen-detected breast cancer	April 2011
Data briefing	Survival of children, teenagers and young adults with cancer in England	April 2011
Data briefing	30-day post-operative mortality after colorectal surgery in England	April 2011
Data briefing	The effect of rurality on cancer incidence and mortality	April 2011

6 *Improving Outcomes: A Strategy for Cancer, Assessment of the Impact on Equalities (AIE)*, DH (January 2011)
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123411.pdf

Document type	Title	Publication date
Data briefing	Where do patients with blood cancers die?	April 2011
Report	Second all breast cancer report	June 2011
Data briefing	Place of death for children, teenagers and young adults with cancer in England	June 2011
Report	<i>Improving Outcomes: A Strategy for Cancer</i> – NCIN Information Supplement	June 2011
Report	What cancer statistics are available and where can I find them?	June 2011
Data briefing	Differentiated teretoma of the testis	August 2011
Data briefing	Rare skin cancer	December 2011
Data briefing	Urgent GP referral rates for suspected cancer	December 2011

Priorities for the coming year

- 1.38 Cancer intelligence will continue to play a critical role in achieving our plans to improve cancer outcomes by empowering patients, supporting clinicians, enabling service providers to focus on the outcomes which matter and assisting commissioners in ensuring that resources are focused on delivering high quality and efficient services. For the year ahead, therefore, we will continue to push to deliver better data and better analyses of data. We need to ensure that data and analyses are user friendly to make them more powerful and relevant to equality groups wherever possible. We need to work with colleagues at all levels in the system to help them use the analyses effectively to provide better information, and thus care, for the public and patients.
- 1.39 A high priority will be to work with key stakeholders to consider how best to make information on cancer services and outcomes more accessible to patients and the public. The service profiles will provide the basis for this.

2 Focus on Public Health Outcomes

Introduction

- 2.1 The total number of new cases of cancer in 2009 was around 265,000, a rise of nearly 10,000 on 2008. Cancer Research UK has recently estimated that about a third of all cancers are caused by smoking, unhealthy diets, alcohol and excess weight; and this proportion increases further when taking into account all lifestyle and environmental factors. This chapter focuses on progress over the past year on prevention and screening and our priorities for the year ahead.

New arrangements for Public Health

- 2.2 From April 2013, certain parts of the national cancer programme will move into Public Health England (PHE). PHE will have responsibility for piloting and roll out of new screening programmes and extensions of existing programmes. (The NHS Commissioning Board will commission existing routine cancer screening programmes.) Other PHE responsibilities will include national coordination and quality assurance of cancer screening programmes, cancer registration and the National Cancer Intelligence Network (NCIN).
- 2.3 The Public Health Outcomes Framework will set out the indicators against which progress will be assessed. In relation to cancer, we are considering the inclusion of the following indicators: cancer screening coverage; mortality from cancer in the under 75s; and the proportion of cancers diagnosed at stages 1 and 2. In addition, we are considering the inclusion of a number of other indicators that will have a longer term impact on cancer, such as rates of smoking prevalence and human papillomavirus (HPV) vaccination uptake. We plan to share the proposed indicator on mortality with the NHS Outcomes Framework. When we publish the Public Health Outcomes Framework early in 2012, we will clarify the nature of the alignment between the NHS and Public Health Outcomes Frameworks, including our approach to alignment of outcomes for cancer.

- 2.4 Subject to the passage of the Health and Social Care Bill, health and wellbeing boards will be established on a statutory basis in every upper-tier and unitary authority in England. They will operate in shadow form from April 2012 and take on their statutory functions from April 2013. The health and wellbeing boards will be the forum to bring together elected councillors, local authority officers, patient representatives and carer representatives and clinical commissioning groups to develop shared understanding of local need, develop joint local priorities, and encourage commissioners to work in a more integrated and joined up manner.
- 2.5 Clinical commissioning groups and local authorities will be required to perform Joint Strategic Needs Assessments and develop joint health and wellbeing strategies through local health and wellbeing boards. We would expect Directors of Public Health to have a role championing and promoting early diagnosis of cancer.

Incidence trends

- 2.6 There were around 265,000 new cases of cancer registered in England in 2009, nearly 135,000 occurred in males and 130,000 in females. This equates to an age-standardised rate of around 424 and 367 per 100,000 population respectively. The number of registrations has increased by around 6,500 new cases for males and 3,300 for females when compared to 2008. The four cancer types of breast, lung, colorectal and prostate account for over half of the cancer burden in England.
- 2.7 Over the last 30 years, the incidence rate in Great Britain for all cancers combined increased by 16% in males and 34% in females, although the majority of the increase occurred before the turn of the century. Since 2000, the age-standardised incidence rates in England have shown a smaller change, with a 3% increase in males and 6% in females.
- 2.8 Cancer can develop at any age, but is most common in older people. More than three out of five new cancers are diagnosed in people aged 65 or over, and over a third are diagnosed in those aged 75 or over. In England between 2000 and 2009 cancer incidence rates in those aged 75+ were relatively stable in males and increased by 6% in females. Over the same period, incidence rates increased for people aged 65 to 74 by 7% in males and 10% in females, whilst for people aged under 65 the increase was 20% in males and 16% in females.

- 2.9 A study published by Cancer Research UK in October 2011 showed that cancer cases are set to grow in number by 45% over the next two decades, from around 298,000 in 2007 to 432,000 by 2030. The study also predicted that, adjusting for the growing and ageing population, cancer rates will remain broadly stable over the period from 2007 to 2020 – at around 400 per 100,000 men per year and 350 per 100,000 women per year.

Mortality trends

- 2.10 Changes in mortality rates reflect changes in both incidence and survival. We talk about survival rates in chapter 3, because this is an indicator within the NHS Outcomes Framework, but here we cover changes in mortality, as cancer mortality changes are an indicator within the Public Health Outcomes Framework – reflecting the role of Public Health in terms of preventing cancer – as well as within the NHS Outcomes Framework.
- 2.11 The latest data for 2008/10 show an improvement in the cancer mortality rate (ages under 75) for England, continuing the previous trend. The cancer mortality rate (ages under 75) was 110.1 deaths per 100,000 population in 2008/10, a decrease of 14.5% since 1999/01 (and 22.0% since 1995/97).
- 2.12 The cancer mortality rate for the areas which had the worst health and deprivation is higher than the England rate, but is also decreasing. In 2008/10, the rate for the areas which had the worst health and deprivation was 128.4 deaths per 100,000 population, a decrease of 13.6% since 1999/01 and 20.7% since 1995/97.
- 2.13 The first chart below presents the latest ten year trend (based on ten rolling three year periods) in the mortality rate from cancer in persons at ages under 75, for England. A comparison between mortality rates for England and the areas which had the worst health and deprivation is shown in Figure 2.2.
- 2.14 Based on 2008/10 data, the absolute gap – ie difference – in cancer mortality rates between England and the areas which had the worst health and deprivation has narrowed by 7.7% since 1999/01 and by 11.6% since 1995/97; although since 2003/05 the gap has remained broadly unchanged.

- 2.15 Work undertaken by the North West Cancer Intelligence Service suggests that there are an estimated 15,000 excess deaths from cancer each year in people aged over 75 in England when compared with other developed countries. Cancer mortality rates in people aged over 75 are not declining as rapidly as they are in the young population. The reasons for this are not fully understood. However, evidence shows older people are less likely to receive curative treatment than younger people.

Figure 2.1. Cancer mortality in England 1999/2001 to 2008/10 for persons under 75

Three year average death rates from cancer in England 1999 to 2001 to 2008 to 2010 for persons under 75

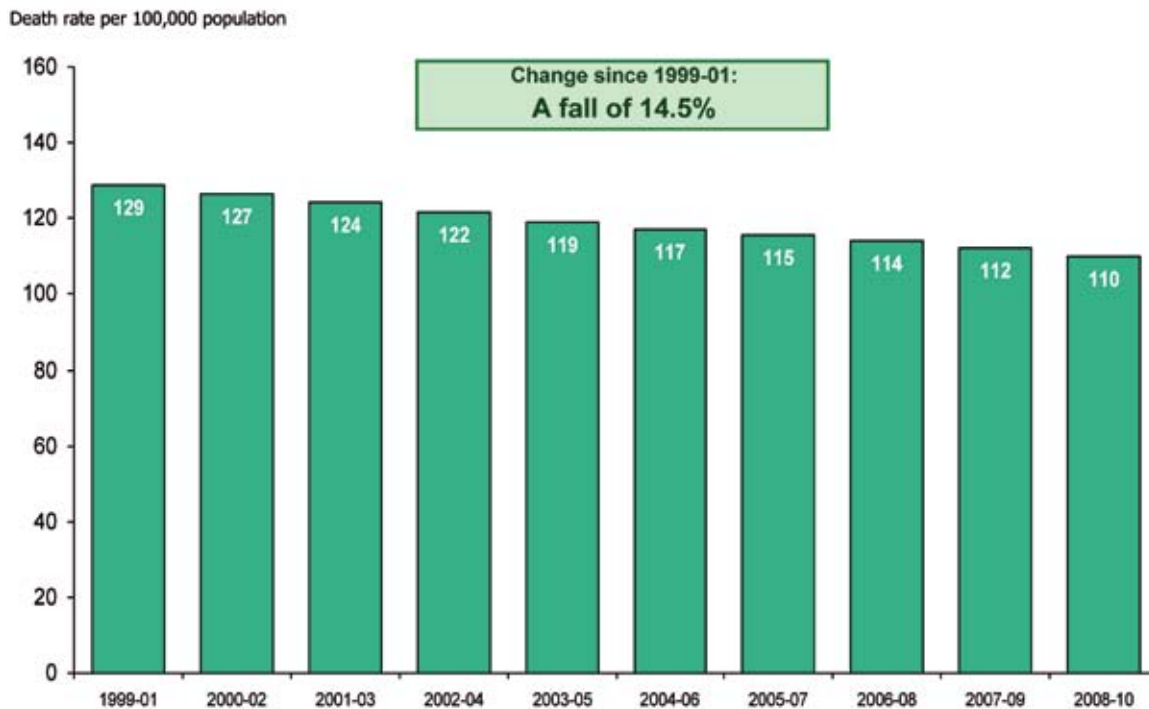
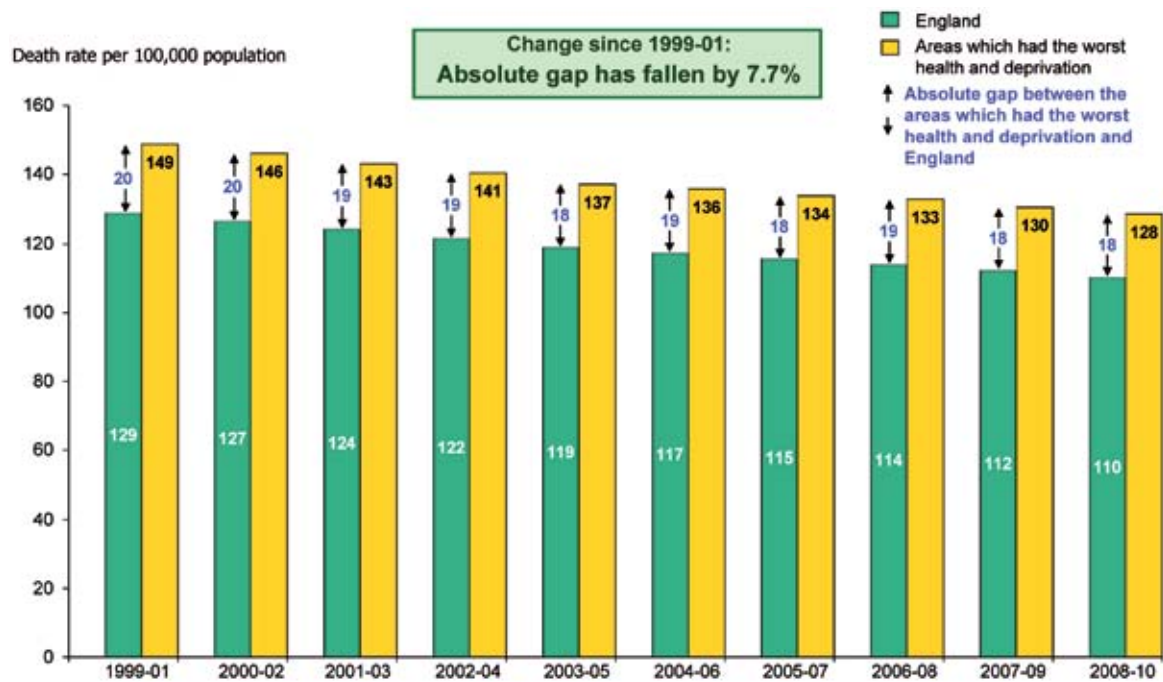


Figure 2.2. Death rates from cancer 1999/2001 to 2008/10 for persons under 75 – areas which had the worst health and deprivation in England

Three year average death rates from cancer 1999 to 2001 to 2008 to 2010 for persons under 75, comparing England and the areas which had the worst health and deprivation



Rates are calculated using the European Standard Population to take account of differences in age structure.

ICD9 data for 2000 have been adjusted to be comparable with ICD10 data for 1999 and 2001 onwards.

Percentage change since 1999 to 2001 is calculated based on unrounded rates.

Figures in the chart are rounded to the nearest integer.

Prevention

Human papilloma virus vaccination programme

2.16 Published preliminary uptake data for human papilloma virus vaccinations given in the year up to June 2011 show that uptake in the routine cohort of 12–13 year-old girls for first (87.4%), second (85.5%) and third (76.6%) doses exceeds that for the same month in the previous two academic years. These are some of the highest uptake figures in the world.

SunSmart

- 2.17 In 2011/12, the DH has been funding Cancer Research UK to deliver the SunSmart skin cancer prevention campaign, primarily targeting young people (age 16-24). Core activities have included developing, promoting and disseminating SunSmart messages and resources to the target audience using effective, credible and measurable channels. The campaign has also worked to support local skin cancer prevention initiatives, to align with other third sector skin cancer prevention initiatives and to extend the reach of its messages through relevant and credible corporate partners.
- 2.18 A major focus for the year was a bespoke marketing partnership with "T4 On The Beach", involving Nicola Roberts of Girls Aloud. At the event itself, around 3,225 of the target audience were directly engaged by the campaign. Evaluation showed that the percentage of people reporting burning "sometimes" over the course of summer 2011 showed a statistically significant drop from 54% in 2010 to 41% this year and those who saw the campaign were more likely to report that they would wear SPF15 sunscreen in the future (72% up from 52%). A multi-channel campaign was also run in the weeks before and after the T4 festival, during which advertorials had an estimated reach of 1.3 million women aged 16-24. Full evaluation of the 2011/12 SunSmart campaign is ongoing.

Sunbeds

- 2.19 The Sunbeds (Regulation) Act came into force in April 2011. The Act makes it an offence for sunbed businesses in England and Wales to permit people under 18 years to use sunbeds on their commercial premises. DH has provided guidance for local authorities on the implementation of the Act, and accompanying information for sunbed businesses, both of which are accessible on the DH website.⁷

Smoking

- 2.20 Tobacco use remains one of our most significant public health challenges. Smoking is the biggest preventable cause of death in England causing more than 80,000 premature deaths each year, and is one of the most significant causes of health inequalities. In 2009, around 29% of all cancer deaths were attributable to smoking.

7 *Sunbeds (Regulations) Act 2010: Guidance on the implementation of the Sunbeds (Regulation) Act 2010*, DH (April 2011)
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125982.pdf

- 2.21 Our Tobacco Control Plan⁸ sets out how tobacco control will be delivered in the context of the new public health system, focusing in particular on the action that the Government will take nationally over the next five years to drive down the prevalence of smoking and to support comprehensive tobacco control in local areas. It includes commitments to:
- implement legislation to end tobacco displays in shops
 - look at whether the plain packaging of tobacco products could be an effective way to reduce the number of young people who take up smoking and to support adult smokers who want to quit, and consult on options. The Department of Health has also commissioned an independent academic review of the existing evidence relevant to the effects of tobacco packaging. This systematic evidence review will be peer reviewed and made available alongside the consultation
 - end sales of tobacco from vending machines from 1 October 2011
 - continue to defend tobacco legislation against legal challenges by the tobacco industry
 - promote effective local enforcement of tobacco legislation, particularly on the age of sale of tobacco
 - continue to follow a policy of using tax to maintain the high price of tobacco products at levels that impact on smoking prevalence
 - encourage more smokers to quit by using the most effective forms of support, through local stop smoking services
 - publish a three year marketing strategy for tobacco control.
- 2.22 Through the comprehensive action described in this plan, we want to reduce smoking rates faster in the next five years than has been achieved in the past five years. The plan sets out national ambitions:
- to reduce adult (aged 18 or over) smoking prevalence in England to 18.5% or less by the end of 2015 (from 21.2%), meaning around 210,000 fewer smokers a year
 - to reduce rates of regular smoking among 15 year olds in England to 12% or less (from 15%) by the end of 2015
 - to reduce rates of smoking throughout pregnancy to 11% or less (from 14%) by the end of 2015 (measured at time of giving birth).

8 *Healthy Lives, Healthy People: A Tobacco Control Plan for England*, DH (March 2011) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_124960.pdf

Obesity

- 2.23 Many types of cancer are more common in people who are overweight or obese, and the importance of this risk factor was underlined in the recent British Journal of Cancer report on lifestyle and environmental issues.⁹ The Government is committed to tackling the major public health challenge posed by high levels of overweight and obesity. In October 2011 it published *A call to action on obesity in England*, which announced two new national ambitions for achieving a downward trend in excess weight in children and adults by 2020. The *Call to action* describes the action that the Government will take and sets out the crucial role that a wide range of partners can play in achieving the ambitions.

Diet and cancer

- 2.24 There is agreement that that diet probably plays an important part in cancer risk, particularly for bowel cancer. To improve the overall balance of the diet, it is advised that high consumers of red and processed meat should reduce their intake, whereas consumption of foods high in fibre (eg wholegrains, fruit and vegetables and cereals) should be increased. The Government actively encourages people to have a healthy balanced diet through the Change4Life campaign, the Public Health Responsibility Deal and NHS Choices. In addition, the Government continues to monitor the population's diet and nutritional wellbeing through the National Diet and Nutrition Survey.

Alcohol

- 2.25 As part of the new Public Health system, local government will be given the responsibility, backed by ring-fenced budgets, to improve people's health, including responsibility for tackling problem drinking. We will set out our plans to achieve this in more detail through announcements in the coming months, as we develop Public Health England. A cross-government alcohol strategy will be published in early 2012. This will cover the range of harms from alcohol (health, violence, dependency, drinking when pregnant, driving and consumption in young people).

Occupational cancer prevention

- 2.26 The World Health Organisation International Agency for Research on Cancer lists over 40 workplace agents or activities as definitely or probably carcinogenic. The Health and Safety Executive (HSE) has

⁹ *The Fraction of Cancer Attributable to Lifestyle and Environmental Factors in the UK in 2010*, British Journal of Cancer, Volume 105, Supplement 2, 6 December 2011

undertaken research estimating the proportion of cancer registrations and deaths attributable to these agents and activities. Based on definite and probable carcinogens, the burden was estimated to be 5.3% (8.2% for men and 2.3% for women) of all cancer deaths recorded in 2005 and 4% (5.7% for men and 2.1% for women) of all cancer registrations in 2004 in Great Britain. For just definite carcinogens, there was a moderate reduction to 4% for all cancer deaths and 3.4% for all cancer registrations.

- 2.27 Lung cancer accounts for the largest proportion of deaths due to occupational causes, followed by mesothelioma, breast cancer and bladder cancer. Lung cancer also accounts for the largest proportion of registrations, followed by non-melanoma skin cancer, breast cancer and mesothelioma. One in two occupational cancer deaths and one in three occupational cancer registrations were due to asbestos. Other carcinogens highlighted were: silica; diesel engine exhausts; mineral oils; shift work; and solar radiation.
- 2.28 HSE have developed estimates of future burden for exposures to test “what if” scenarios and to provide information to persuade industry and workers of the importance of properly controlling carcinogens in the workplace.

Aspirin and prevention

- 2.29 We have been working with Cancer Research UK to review the evidence that low dose aspirin for several years may reduce cancer mortality. We are considering a range of issues, such as when the benefits might be outweighed by the disadvantages (particularly, the increased risk of gastric bleeds) and how best to manage the use of aspirin in the general public for this purpose (for example, should people seek advice from their GP or pharmacist?). We understand that an international consensus document on aspirin and cancer is likely to be published in 2012.

Screening

Cervical screening

- 2.30 Advice to the NHS on implementing HPV testing as triage in the NHS Cervical Screening Programme was issued in July 2011, and the NHS Supply Chain Framework on purchasing HPV testing kits was published in September 2011. Once local programmes have implemented HPV triage in 2011/12, the expectation is that they will implement HPV test of cure in 2012/13, with combined savings of £16 million a year from 2013/14

onwards. As at the end of November 2011, latest figures from the Open Exeter system show that over 98% of women were receiving the results of their cervical screening tests within two weeks.

Breast cancer screening

- 2.31 As at November 2011, 42 out of 80 local programmes (53%) had entered the breast screening age extension randomisation trial, and a further 8 (10%) which are unsuitable for randomisation were inviting only the 47 to 49 year-olds. 63% of local programmes are now taking part in the project. The randomisation trial will become the world's largest randomised controlled trial on any subject. It is already as large as any previous breast screening trial. As at November 2011, 37 (46%) of local breast screening programmes were fully digital and 69 (86%) had at least one digital mammography set. 11 local programmes still have not converted to digital mammography, despite the clinical and long-term cost saving benefits.
- 2.32 Our breast cancer screening programme has always been regularly scrutinised and evaluated. We know that some scientists differ in their views towards screening so, in order to find consensus, the National Cancer Director, Professor Sir Mike Richards, is commissioning a review of the evidence in partnership with Dr Harpal Kumar, Chief Executive of Cancer Research UK. An independent panel of experts is being put together to carry out the review. The DH will look at the findings of the review, which are expected in 2012.

Bowel cancer screening

- 2.33 As at the end of November 2011, over 12.2 million bowel cancer testing kits had been sent out and over 6.9 million returned. 10,785 cancers had been detected and 53,616 patients had undergone polyp removal. 33 out of 58 local screening centres have now extended their programmes to men and women up to their 75th birthday. There have been some issues around endoscopy provision in some parts of the country which has meant some programmes were not able to implement the age extension on time. Work to improve endoscopy capacity and productivity is addressed elsewhere in this report. The IT system to support the pilots of flexible sigmoidoscopy screening is now under development, and local bowel screening programmes will be invited to become pilot sites in early 2012. We still aim to meet the IOSC commitment of 60% coverage across England by March 2015.

Priorities for the coming year

- 2.34 Priorities for the coming year mainly surround implementation – implementing the Government’s strategies on prevention, and continuing the expansions of the cancer screening programmes. Until the outcome of the independent review of breast cancer screening is known, the Government’s line is clear – women should make the choice to go for breast screening when invited, and we remain committed to the randomisation project and the conversion to digital mammography. We will know the first pilot sites for the implementation of flexible sigmoidoscopy early in 2012, and we hope actions outlined in the next chapter allow us to begin to tackle the challenges of endoscopy capacity. We also need to ensure that the commissioning and delivery of the cancer screening programmes are managed smoothly to the new health system.

3 NHS Outcomes Framework

Domain 1: preventing people from dying prematurely

Introduction

- 3.1 The purpose of the NHS Outcomes Framework is to present a focussed and balanced set of national goals and supporting indicators which patients, the public and Parliament will be able to use to judge the overall performance of the NHS.
- 3.2 It will also be the mechanism through which the Secretary of State for Health can hold the NHS Commissioning Board to account for outcomes it is securing for patients. The NHS Outcomes Framework is structured around five domains, which set out the high-level national outcomes that the NHS should be aiming to improve. Each domain includes a number of indicators. The domains focus on:
- Domain 1:** Preventing people from dying prematurely
 - Domain 2:** Enhancing quality of life for people with long-term conditions
 - Domain 3:** Helping people to recover from episodes of ill health or following injury
 - Domain 4:** Ensuring that people have a positive experience of care
 - Domain 5:** Treating and caring for people in a safe environment; and protecting them from avoidable harm.
- 3.3 This and the following four chapters are structured using these domains as headings, to demonstrate how the work that is being done to implement *Improving Outcomes: a Strategy for Cancer* (IOSC) supports improvements in these overarching outcomes.
- 3.4 IOSC set out a commitment to deliver improved cancer survival rates. In line with Domain 1 of the NHS Outcomes Framework, it sets out an ambition to save an additional 5,000 lives per year by 2014/15 – which is designed to make England match the European average for survival rates. Work is ongoing to set a formal level of ambition in line with the NHS

Outcomes Framework Domain 1 indicators on survival rates but, in the meantime, we are moving forward on actions to support improved survival rates. This chapter reports on these actions.

National Awareness and Early Diagnosis Initiative (NAEDI)

Funding

- 3.5 IOSC emphasised the need to diagnose cancer earlier if survival rates are to be brought up to the European average and then to be amongst the best in Europe. Central to these plans is an investment of £450 million additional funding to achieve earlier diagnosis, supporting a range of activities including meeting the costs for additional diagnostic investigations and treatments.
- 3.6 The Operating Framework for the NHS in England 2011/12 required the NHS to implement the priorities set out in IOSC to ensure that patients had timely access to diagnosis and treatment. The priority for this year has been to ensure that the NHS is planning sufficient capacity in endoscopy services to meet the short and longer-term demand in response to progress in bowel cancer screening and the earlier diagnosis of symptomatic bowel cancer patients. Timely access to diagnosis and treatment continue to be priority areas next year, as reflected in the Operating Framework for the NHS in England 2012/13.

Regional bowel and lung cancer symptom awareness campaigns

- 3.7 This year, we piloted public campaigns to promote awareness and earlier diagnosis of bowel and lung cancer. Under the brand *Be Clear on Cancer*, both campaigns used TV, radio and print advertising. There were also face-to-face events run in shopping centres so the public could talk to trained staff. Aimed at people over the age of 55 for the bowel campaign and those over 50 for the lung campaign, the campaigns were designed to keep the message simple by focussing on the key cancer symptoms, providing a clear call to action to see the doctor and giving assurance that earlier diagnosis improves the chances of successful treatment. Cancer networks ensured that the local primary and secondary care clinical community was aware of the campaign plans and key messages. Dedicated resources were also developed for practice staff and GPs, to support them in responding to patients who attended local surgeries having seen the campaigns.



- 3.8 The bowel cancer campaign ran in the East of England and the South West at the end of January 2011, for eight weeks, encouraging people with loose poo or blood in poo for more than three weeks to see their doctor. The evaluation showed that:
- recognition of the messaging was high, at 80% in South West England and 72% in East of England
 - in both regions, more people went to see their GP with bowel cancer symptoms and there was about a 50% increase in presentations with the symptoms used in the campaign
 - the increases in attendances to primary care equated to approximately one additional patient per practice for each week of the campaign
 - comparing the six-month periods January to June 2010 and 2011, the number of urgent GP referrals for suspected bowel cancer increased

by 32% suggesting a positive response beyond the end of the campaign

- in endoscopy services there was a 28.5% increase in the number of people waiting for a colonoscopy in the East of England and a 16.4% increase in the South West. Some Trusts in the centre of the television coverage saw up to a doubling in colonoscopy waits
- when comparing the campaign period (January to March 2011) with the same period in 2010, there was no significant difference in the number of bowel cancers detected and no difference observed in those cancers diagnosed at an early stage.

3.9 It is not surprising that we have not yet seen a significant increase in the numbers of bowel cancers diagnosed as a result of the campaign or improvements in the stage at which cancers were diagnosed because:

- the campaign pilots were for a short period only
- it takes time to change behaviours significantly
- it could well be that a campaign would initially impact mostly on people with more severe symptoms, with cancer at a later stage, and encourage them to go to the doctor.

3.10 The results have provided some important lessons for our future campaigns:

- the campaign had a positive effect in terms of improving the public's knowledge of cancer symptoms and promoting behaviour change
- there was strong public support for government campaigns of this kind, with 96% of those surveyed supporting the aims of the campaign
- based on the increases in colonoscopies and flexible sigmoidoscopies, we estimated that a minimum of 23 additional bowel cancers will have been prevented by the campaign because potentially cancer causing polyps will have been discovered and removed, and 14 lives will have been saved by diagnosing the cancers earlier (we intend to pilot an approach for collecting these data more systematically)
- we need to sustain campaigns of this kind.

3.11 We are working with Cancer Research UK on an evaluation of the campaign activities, which will be published shortly.

- 3.12 Based on the experience of this pilot, we are rolling out a national bowel cancer campaign in January 2012. We wrote to the NHS in August 2011 to ask them to plan for the extra demand, particularly to ask the service to ensure there was sufficient capacity in endoscopy and histopathology services. Projections have been provided on the likely increased demand for endoscopy services as a result of the campaign.
- 3.13 For the national campaign, we have estimated that there will need to be an additional 15,000 colonoscopies across England, which will mean approximately 100 additional colonoscopies for an average sized NHS Trust. Most of the additional colonoscopies will be spread over a 10-week period, and so an average Trust will need to undertake around 10 additional colonoscopies per week for 10 weeks. Funding for these additional tests was put into commissioner baselines as part of the funding associated with IOSC.
- 3.14 Drawing on the experience of local PCT and Trust led initiatives on raising the awareness of the signs and symptoms of lung cancer, a lung cancer campaign was piloted in the Midlands and border areas in October 2011. The key message here was people who have had a cough for three weeks or more should tell their doctor. We expect early results from the campaign in January 2012.



Local campaigns in 2010/11 to achieve earlier diagnosis of cancer

- 3.15 A total of £9 million was allocated to PCTs in 2010/11 to run local awareness and early diagnosis initiatives, targeting breast, bowel and lung cancers. Of the 59 projects originally funded some have now merged, resulting in 52 projects covering 109 PCTs across the country. These community based initiatives used a range of social marketing techniques to reach local people. 83% of the projects ran community events to engage members of the public.
- 3.16 A number of Trusts have implemented service or pathway changes to improve early diagnosis such as identifying high-risk patients, direct access to flexible sigmoidoscopy or improving the turnaround time for results. Clinical engagement was a key activity. Based on PCT reports, it is estimated that these initiatives have reached around 13.6 million people.
- 3.17 An example of a collaborative project was in Manchester, where 40% of those interviewed in a post-activity survey had seen, read or heard something from the campaign. A third of South Asians have seen the

“Detect Cancer Early” bowel and breast advertisements on television. 4% of people who saw any item of campaign material made an appointment to talk to their GP as a result of seeing the campaign.

- 3.18 As an example of a single PCT project, in Cumbria 51% of people recalled seeing any information on lung cancer post-campaign, a significant increase from the 37% pre-campaign. Smokers showed a highly significant increase in awareness and the “fatalistic” group (perceiving themselves as having little control over their health), who had the lowest initial awareness of lung cancer advertising, showed a significant increase in awareness post-campaign. 65% of the total sample recognised the “cough cough” brand used by the project. The proportion of the total sample who said they would visit the doctor if they had a bad cough increased significantly from 70% pre-campaign to 82% post-campaign.

Embedding equality in public awareness campaigns

- 3.19 The national bowel campaign will provide an opportunity to ensure the messages reach specific communities. We will promote the campaign on popular ethnic TV and radio channels and we are working with the National Cancer Action Team (NCAT) to use the cancer community ambassadors on Bengali and Ghanaian radio stations. We also intend to extend our partnership work with Black and Minority Ethnic (BME) cancer charities and community organisations.

Identifying the cancers to be targeted for earlier diagnosis work

- 3.20 Based on the research evidence of Abdel-Rhaman and colleagues¹⁰, we have estimated the number of deaths which could be avoided within five years of diagnosis in England if survival matched the best in Europe. These figures are based on patients diagnosed in the late 1990s.

10 Abdel-Rahman et al, *What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable?*, Br J Cancer. 2009 Dec 3; 101 Suppl 2:S115-24 www.ncbi.nlm.nih.gov/pubmed/19956155

Figure 3.1. Avoidable deaths pa if survival in England matched the best in Europe: Total around 10,000 avoidable deaths pa

Breast	~ 2000	Myeloma	250
Colorectal	~ 1700	Endometrial	250
Lung	~ 1300	Leukaemia	240
Kidney/Bladder	~ 990	Brain	225
Oesophagogastric	~ 950	Melanoma	190
Ovary	~ 500	Cervix	180
NHL/HD	370	Oral/Larynx	170
		Pancreas	75

[NB Prostate has been excluded as survival 'gap' is likely to be due to differences in PSA testing rates.].

- 3.21 If we were to focus solely on breast, bowel and lung cancer, survival rates would have to match the best in Europe by 2014/15, rather than the European average, to achieve our ambition of saving an additional 5,000 lives every year by 2014/15. It is unlikely that this is achievable in that timeframe, so it is important that we also make efforts to improve survival rates in the less common cancers.
- 3.22 For 2011/12, we have therefore funded PCTs to trial public awareness campaigns to achieve earlier diagnosis of oesophagogastric, bladder and kidney cancers. These will be rolled out from January 2012. We wished to trial a campaign based on symptoms that could be relevant to more than one cancer, to see if we could get greater impact from such an approach. The focus is therefore on the symptom of blood in urine, which is common to kidney and bladder cancer.
- 3.23 In addition, we have funded a range of local projects to raise awareness of breast cancer symptoms among women over 70. Because screening for breast cancer has previously ended at 70, women may have mistakenly thought that their risk of breast cancer was over, whereas it increases with age. The campaign is part of a broader programme to try to improve mortality and survival rates for older people by tackling late diagnosis and ensuring appropriate levels of intervention.
- 3.24 As we said in IOSC, much of society is already involved in supporting cancer care, and IOSC set out our Big Society plans to build on this. One of the main areas that we have focused on over the past year is in relation to tackling late diagnosis. This includes developing a partnership with a range of organisations to raise awareness of cancer signs and

symptoms among their employees – and also to support our symptom awareness campaigns with the public.

GP engagement

- 3.25 Although GPs only see around eight or nine new cancer patients each year, they see many more patients presenting with symptoms that could be cancer, which are the symptoms of other conditions too. A range of support is available to help GPs assess when it is appropriate to refer patients for investigation for suspected cancer, such as NICE referral guidelines, but we want to do more to support them.
- 3.26 In 2011/12 cancer networks have been funded to support GPs to diagnose cancer earlier. This is through a range of work eg continuing professional development, preparing for patients coming to the surgery as a result of public awareness campaigns and audit. NCAT and cancer networks are disseminating tools, guidance, training and best practice to GPs, including: National Cancer Intelligence Network (NCIN) GP practice profiles, new information on safety netting, training materials and on-line resources for GPs and practice staff. NCAT has also invested more to build capacity for GP leadership in cancer, with 87 additional sessions funded in 2011/12. GP leaders are working with general practices so that they are able to respond more positively to early diagnosis by reflecting on and changing their own practice and promoting systems changes to improve early diagnosis.
- 3.27 Cancer Research UK are working with the NCAT to develop a broader GP engagement programme for the coming years, including face-to-face interactions, the use of doctors.net and working with the senior leadership of the Royal College of General Practitioners (RCGP) on a strategic initiative.
- 3.28 In November 2011, the RCGP published its report on the national audit of cancer diagnosis in primary care¹¹. Prior to this audit, there had been limited available data in this country on the interval from symptom onset to diagnosis in primary care for most cancers. Based on data across 1,170 general practices, the report provides insight into the factors that might influence late diagnosis of cancer in general practice. The report shows that three quarters of patients with symptoms of cancer in England are assessed, investigated and referred within a month of presenting to their

11 National Audit of Cancer Diagnosis in Primary Care, Royal College of General Practitioners, Clinical Innovation and Research Centre, 2011
www.rcgp.org.uk/pdf/National_Audit_of_Cancer_Diagnosis_in_Primary-Care.pdf

GP. However, referral times varied by cancer type and the report highlighted the importance of better GP access to diagnostic tests for some cancers.

GP access to diagnostic tests

3.29 Until now GPs in general have had very limited direct access to relevant diagnostics, except chest x-ray. To gain access to these tests patients have had to be referred to secondary care. That is why IOSC set out our aims to improve GP access to the four priority areas of diagnostics identified as being appropriate as first tests by the Cancer Diagnostics Advisory Board (CDAB). These are:

- chest x-ray: to support the diagnosis of lung cancer
- non-obstetric ultrasound: to support the diagnosis of ovarian cancer
- flexible-sigmoidoscopy/colonoscopy: to support the diagnosis of bowel cancer
- Magnetic Resonance Imaging (MRI) brain: to support the diagnosis of brain cancer.

3.30 To support this objective, we have:

- produced referral best practice information for GPs – a working group of the CDAB has produced this information, which aims to enable GPs to make best use of direct access pathways where they are available to them. The draft is currently out for informal consultation with a wide range of key stakeholders. We hope to make it available early in 2012. Macmillan Cancer Support have also started work to incorporate the information into their existing desktop aid for GPs that outlines existing rapid referral guidelines
- mapped out best practice pathways – the Diagnostics Improvement Team at NHS Improvement is developing best practice pathways for each of the four priority areas for diagnostics to support service providers and commissioners in the establishment of direct access services
- developed a new data collection – see chapter 1
- assessed how we might use tariffs to incentivise greater GP access to diagnostic tests – from 2012/13 we will have tariffs for direct access flexible sigmoidoscopies.

Cancer waiting times

- 3.31 IOSC and its accompanying *Review of Cancer Waiting Times Standards*¹² concluded that the requirements for the NHS to meet maximum waiting times for cancer services should be retained, stating:

"The outcome of the review 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 requirements will therefore be retained."

- 3.32 Since this decision, national performance has been sustained, with the NHS meeting the expected performance levels nationally. The following table details the levels of achievement for Quarter Two 2011/12 and the levels the NHS is expecting to meet (the "operational standards"). These operational standards allow for the fact that not all patients wish to be seen or treated within the required time and that there will be a proportion for whom treatment within these times is not clinically appropriate. The Operating Framework for the NHS in England 2012/13 states: "We expect all four of the 31 day operational standards and all three of the 62 day operational standards to continue to be met or exceeded."

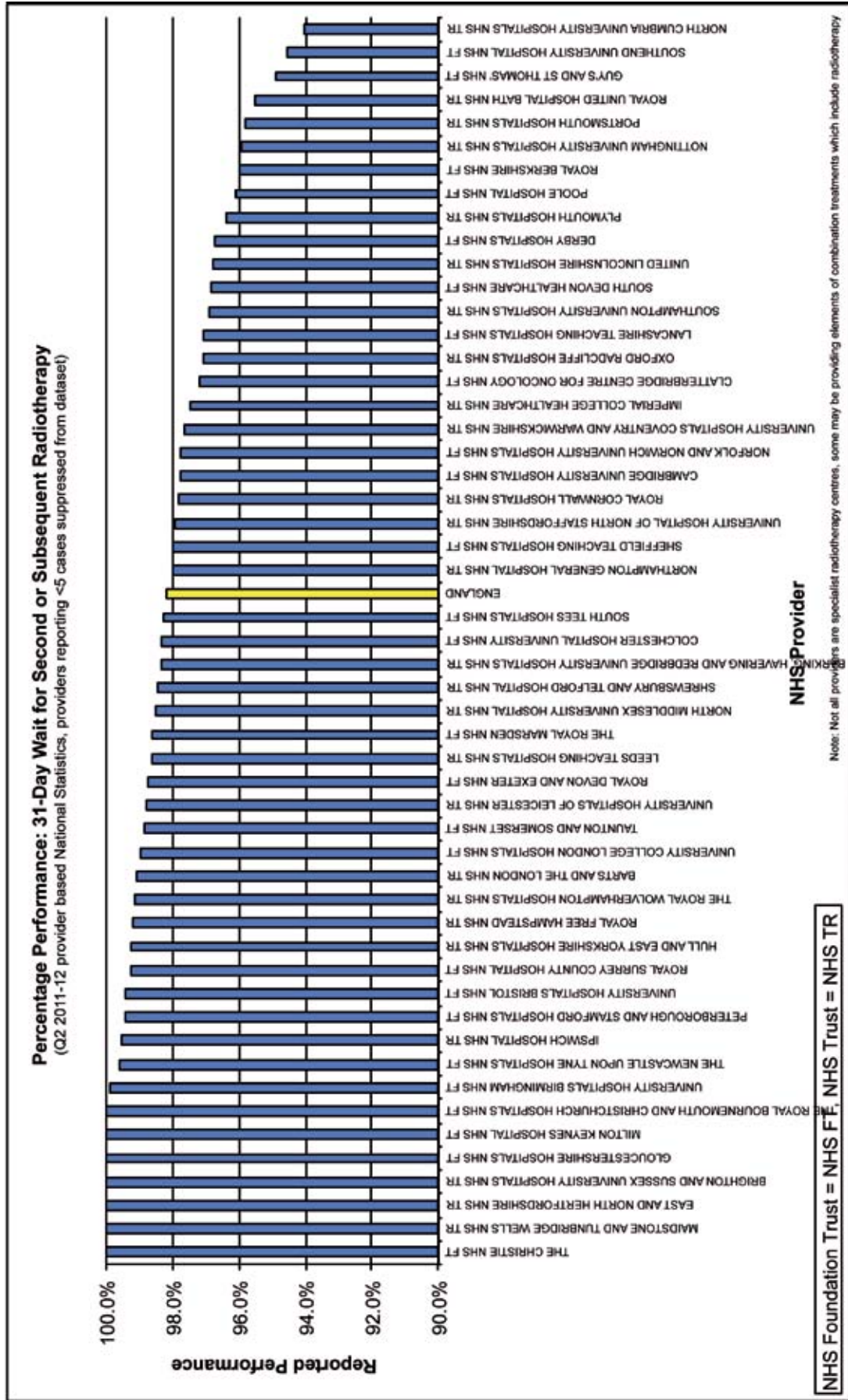
12 www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123395.pdf

Table 3.1. Waiting times for suspected and diagnosed cancer patients

Waiting Time Measure	Level within the Operating Framework for the NHS in England (2012/13)	Operational Standard ¹²	Quarter Two 2011/12 Achievement (All data are provider based national statistics)
All cancer two-week wait	Headline Quality Measure	93%	95.7%
Two-week wait for breast symptoms (where cancer was not initially suspected)	Headline Quality Measure	93%	96.0%
Two month (62 day) urgent GP referral to first treatment wait for all cancers	Headline Quality Measure	85%	87.3%
62 day wait for first treatment following referral from an NHS cancer screening service	Headline Quality Measure	90%	93.2%
62 day wait for first treatment following a consultant's decision to upgrade the priority of the patient	Headline Quality Measure	None set; this has been left for local implementation	93.4%
One month (31 day) diagnosis to first treatment wait for all cancers	Supporting Quality Measure	96%	98.4%
31 day wait for second or subsequent treatment – surgery	Supporting Quality Measure	94%	97.7%
31 day wait for second or subsequent treatment – anti-cancer drug regimens	Supporting Quality Measure	98%	99.8%
31 day wait for second or subsequent treatment – radiotherapy	Supporting Quality Measure	94%	98.2%

13 RE: Operational Standards for the Cancer Waiting Times Commitments, letter to NHS Chief Executives from the NHS Medical Director, 30th July 2009 (Gateway reference 12320) www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103431.pdf

Figure 3.2. Achievement of the 31-day maximum waiting time for second or subsequent radiotherapy



Changes and variations in urgent two-week wait referrals

- 3.33 Early diagnosis and treatment of cancer is an important factor in improving outcomes for cancer services. In addition to programmes targeted at the population such as awareness campaigns and population based screening for cancer, providing fast access to efficiently managed services remains key to ensuring a patient moves along their pathway of care towards diagnosis and treatment in the most timely and appropriate manner.
- 3.34 Since the introduction of the cancer two-week wait there has been a steady increase in the number of patients referred urgently for suspected cancer by their GP. In Quarter One 2001/02 the number of patients reported was 77,331. Though the methods used to calculate these statistics have since changed, there has been an obvious increase in patient numbers over the last ten years. The number of patients being first seen by a specialist at an English NHS provider following an urgent referral now stands at 274,995 (Quarter Two 2011/12), with over a million urgent referrals a year, although this is less than originally anticipated.
- 3.35 Below the significant national increase in the use of the urgent referral pathway, enabling patients to be seen within two weeks, there remain significant local variations in the use of two-week wait services. Figures have shown that 18 PCTs have two-week wait referral rates of 15/1000 population whilst five PCTs have rates above 25/1000 population.

Radiotherapy

- 3.36 From 31 December 2010, the NHS has been required to deliver second or subsequent radiotherapy treatments within a maximum waiting time of 31 days. Since the introduction of this requirement the NHS has met the operational standard. The operational standard allows for the fact that a certain proportion of patients will not be available to begin treatment within 31 days, either for personal reasons or because it is not clinically appropriate. For Quarter Two 2011/12, nationally, 98.2% of patients began their course of subsequent radiotherapy within 31 days, though there was variation at a local level.
- 3.37 The following chart illustrates the reported level of achievement of this measure for all organisations providing these services to more than five patients within Quarter Two 2011/12¹⁴.

14 www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Perfomedataandstatistics/HospitalWaitingTimesandListStatistics/CancerWaitingTimes/index.htm

Other treatment issues relevant to improving survival rates

Tackling variations

- 3.38 Over the course of the year, NCIN has continued to publish data to support the NHS in tackling variations in services and outcomes. This has included, for example, the report on NHS treated cancer patients receiving major surgical resections¹⁵ and the data briefing on the incidence of, and survival rates in England from, soft tissue sarcomas¹⁶.

Making sure older people have access to appropriate interventions

- 3.39 Undertreatment of older people may happen because assumptions are made about an older person's ability to tolerate treatment without undertaking a full assessment of their health. Furthermore, lack of practical support, such as transport, presents a barrier to some older patients receiving treatment.
- 3.40 In partnership with Macmillan Cancer Support we are funding a two year pilot programme to improve intervention rates for people over 70 who have a cancer diagnosis. Through the "Improving Cancer Treatment, Assessment and Support for Older People Project" we are co-funding five pilot sites to:
- test and evaluate new methods of clinical assessment of people with a diagnosis of cancer (through a Comprehensive Geriatric Assessment)
 - coordinate and deliver short-term practical support packages for older people undergoing treatment for cancer
 - promote age equality to address age discriminatory behaviour in cancer services.
- 3.41 The five pilot sites, which started testing new models of care for older people aged 70 and over from May 2011, are running in Merseyside and Cheshire Cancer Network, North East London Cancer Network, South East London Cancer Network, Sussex Cancer Network and Thames Valley Cancer Network. The pilots will run until September 2012 and a project report which will include recommendations and examples of good practice will be published by the end of 2012.

15 Major resections England, 2004-2006, National Cancer Intelligence Network, March 2011 www.ncin.org.uk/view.aspx?rid=540

16 Soft Tissue Sarcomas: incidence and survival rates in England, National Cancer Intelligence Network, 2010 www.ncin.org.uk/publications/data_briefings/soft_tissue_sarcoma.aspx

POI/NCEI project

- 3.42 Working in partnership, the National Cancer Equality Initiative (NCEI) and the Pharmaceutical Oncology Initiative (POI) have commissioned research to explore how age-related characteristics influence clinical decisions. The research considered breast cancer, non-Hodgkin's lymphoma, chronic myeloid leukaemia, early stage bowel cancer and renal cell cancers. A conjoint analysis model was used to replicate physician behaviour. This approach works by presenting cancer doctors with a series of patient scenarios, which include alternating variables of age/cancer stage/co-morbidities and social support, before using this analysis to predict behaviour. The results, which will be formally published shortly, show that age, regardless of co-morbidities and other variables, is a significant factor in treatment decisions.

Cancer does not discriminate campaign

- 3.43 This campaign was formally launched in the House of Commons on 7 December 2011, but work has been underway for some time. The campaign aims to work with a range of partners and stakeholders to raise awareness of the early signs and symptoms of cancer in BME communities.
- 3.44 To mark Ethnic Minority Cancer Awareness Week (EMCAW) in July 2011, a partnership with *The Voice* newspaper led to a health supplement being produced in collaboration with 14 organisations, reaching more than 60,000 people of African and African Caribbean origin (see below). Asian and Irish supplements will be published in 2012, using a similar partnership approach. The campaign will be targeted in London, Birmingham, Nottingham, Leicester and West Yorkshire.

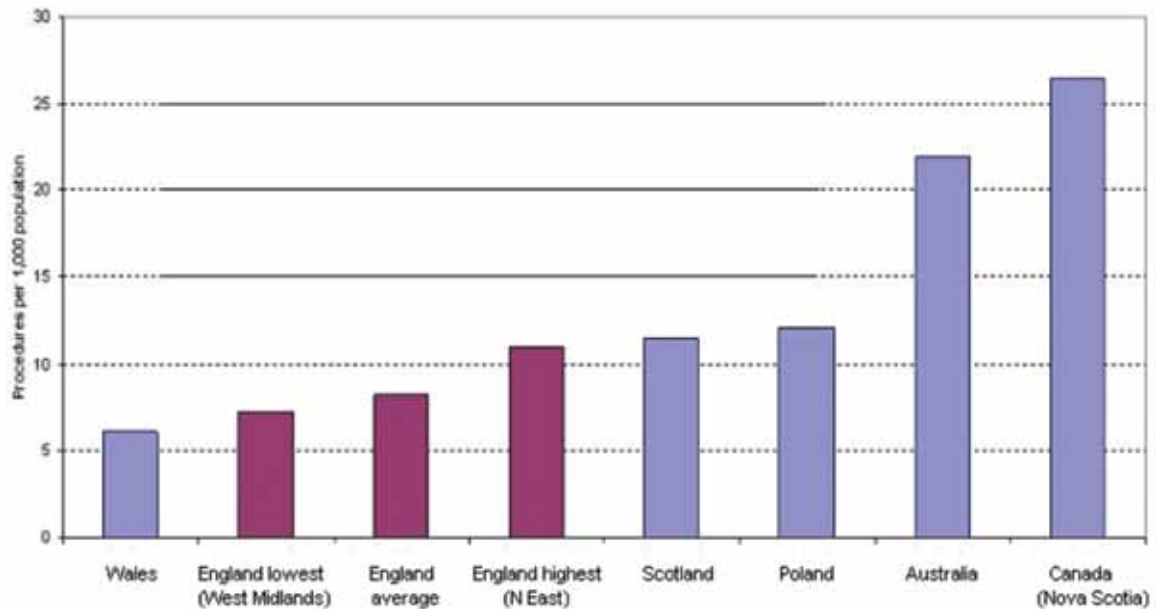


3.45 A partnership has been formed with the Spectrum radio network to pilot an innovative approach to reaching the Bangladeshi and Ghanaian communities. Two radio presenters have been trained as community ambassadors to signpost people in their respective communities, as well as to use their radio shows to bring important messages around cancer awareness to these communities, signposting them to further information and advice on what they should do if they are worried. The pilot also includes interviews with healthcare professionals on the radio.

Priorities for the coming year

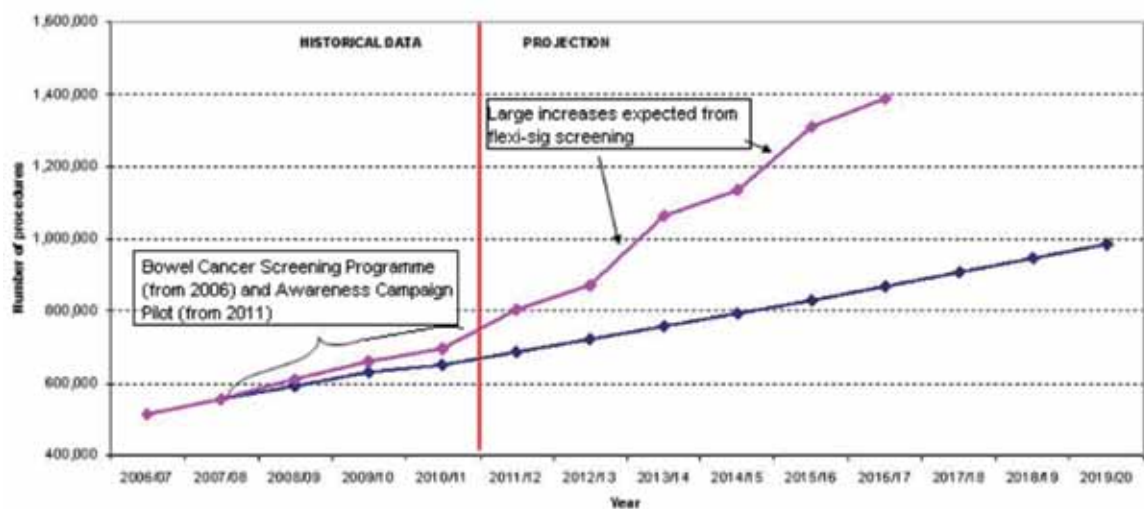
3.46 The age extension to the bowel cancer screening programme, the introduction of flexible sigmoidoscopy bowel screening and the move to more investigations of symptomatic patients mean that a key priority for next year is to increase endoscopy activity. As shown below, we are starting from a low level, with much lower rates of endoscopy than many other countries.

Figure 3.3. International comparisons – crude colonoscopy rates per 1,000 in 2010/11



3.47 We have modelled the impact of the changes and they show that the NHS needs to plan for a year on year increase of around 10-15% each year.

Figure 3.4. Historic and projected endoscopic procedures in England, 2006/07 to 2019/20



Note: For the historical data the difference between the pink and blue lines largely reflects the current impact of bowel screening on endoscopy.

3.48 The funding for the necessary increase in endoscopies has been put into PCT baselines. While it is primarily for the NHS to take the necessary steps to increase endoscopy activity, we are also looking at the scope for support centrally, eg through service improvement work. The Operating Framework for 2012/13 has made it clear that the NHS is expected to have less than 1% of patients waiting more than six weeks for a diagnostic test and this should be very helpful in ensuring there is sufficient endoscopy capacity.

3.49 Other priorities include:

- a range of campaigns at national, regional and local level to continue to raise awareness of the symptoms of cancer
- further work on developing the levels of ambition for the cancer indicators in the NHS Outcomes Framework
- providing benchmarked data to the NHS so that NHS organisations can see the variations in services and outcomes, as a lever for improvements
- developing a broader GP engagement programme.

4 NHS Outcomes Framework

Domain 2: quality of life for people with long-term conditions

Introduction


- 4.1 As more cancer patients survive for longer periods, it is essential that the focus of treatment and care is not just on immediate survival, but on ensuring that cancer survivors have as good a quality of life as possible. This chapter reports on a range of work underway to deliver this.

Reducing possible late effects of treatment

Intensity modulated radiotherapy

- 4.2 We know that targeted radiotherapy can reduce the risk of long-term damage for cancer patients. Intensity modulated radiotherapy (IMRT) has the capability to reduce damage to normal healthy tissue by reducing treatment margins and potentially allowing clinicians to escalate the dose. This is believed to lead to both improved cure rates and reduced side effects with the subsequent reduction in the need to manage long-term, serious toxicities. Almost all linear accelerators are now IMRT capable and enabled.

Cost effectiveness of intensity modulated radiotherapy (IMRT) for head and neck cancers

Avon, Somerset and Wiltshire 
Cancer Services

In 2009/10 approximately 300 patients were diagnosed with cancers of the head or neck within Avon, Somerset and Wiltshire (ASW) cancer network. Of these patients, around 68-70% (207) would receive radiotherapy and, of these, approximately 80% (166 patients) would be expected to derive benefit from and therefore be treated with IMRT.

The incidence of xerostomia (dry mouth) 24 months after treatment falls from 83% with conventional radiotherapy to 29% with IMRT for patients with common head and neck cancers¹⁶. Total xerostomia is a major problem, as up to 95% of patients lose all of their natural teeth within the two to four years following radiotherapy. Dentures are then constructed, but this can often be unsuccessful as lack of saliva hampers retention. Implant-retained and supported dental prostheses are then attempted. These interventions are very expensive and time consuming and are made more complex as the bone has received radiotherapy which delays healing.

Another issue for these patients is osteo-radionecrosis, a problem with bone healing that can occur in people who have received high doses of radiation, particularly to the jaw. Areas of bone treated with radiation lose their ability to heal resulting in pain and fragility and any subsequent infections can pose a huge risk to the patient. It can be treated with antibiotics or steroids in the first instance and hyperbaric oxygen therapy (oxygen delivered in a pressurised chamber) can be used to increase the amount of oxygen given to the affected tissues to improve the chance of healing, but is very expensive. If all the above interventions fail, the dead bone has to be surgically removed. IMRT is expected to reduce the likelihood of this although it does not offset the importance of meticulous dental hygiene measures before, during and after radiotherapy¹⁷.

ASW cancer network estimate that IMRT is cost-saving in the long run due to savings on medication and expensive dental treatment. Avoiding dry mouth means IMRT patients have a higher quality of life and a recent phase 2 study indicates a potential 16% increased cure rate using IMRT to intensify the dose of radiotherapy¹⁸. This is being tested in a national phase 3 study.

- 17 Nutting et al *Parotid-sparing intensity modulated versus conventional radiotherapy in head and neck cancer (PARSPORT): a phase 3 multicentre randomised controlled trial*. *Lancet Oncol* 12 (2011) 127-136
- 18 Ben-David et al *Lack of Osteoradionecrosis of the mandible after IMRT for head and neck cancer; Likely contributions of both dental care and improved dose distributions*. *Int J Radiat Oncol Biol Phys* 68 (2007) 396-402
- 19 Guerrero et al, *A phase I study of dose-escalated chemoradiation with accelerated intensity modulated radiotherapy in locally advanced head and neck cancer*. *Radiotherapy and Oncol.* 85 (2007) 36-41

- 4.3 The National Radiotherapy Implementation Group (NRIG) has advised that 33% of radical fractions should be delivered using IMRT. This is set out in the Cancer Action Team (NCAT) IMRT commissioner guidance published on its website in 2009. Of the 28 cancer networks, 23 have one or more radiotherapy centres providing IMRT with 31 of 50 centres providing it at some level.
- 4.4 We know that, in 2008, 885 patients had IMRT in England; by 2010 this figure had already risen to 3,398 patients (this represents 5% of all radical episodes). This figure is expected to rise significantly when the 2011 data are analysed. The NRIG are reviewing these data. The National Radiotherapy Advisory Group recognised the clear role for 4D Adaptive Radiotherapy as the standard of care. As we increase the use of IMRT, commissioners and services should begin planning the increased use of image guided radiotherapy (IGRT).
- 4.5 Data from the radiotherapy data set has been embedded within the Cancer Commissioning Toolkit, allowing improvements in IMRT usage to be monitored. Reports are being made available to commissioners to monitor key measures, including uptake of IMRT, on a quarterly basis. Some of these reports are now available, with others due to be included in the toolkit in January 2012. These reports will soon include 18 key metrics on radiotherapy provision and delivery to support stronger commissioning and greater information.

Proton beam therapy

- 4.6 We continue to work on the development of a national proton beam therapy (PBT) service in this country and have completed the first phase of the project development process. We are now fast tracking the next phase so that we will know what a national service may look like, in terms of the numbers and location of facilities, by the end of March 2012.
- 4.7 Until facilities can be built in England, we will continue to fund treatment abroad for patients who meet clearly defined criteria. In July 2011, the age profile and detail of diagnosis for paediatric cases was expanded and, as of the end of November 2011, 83 paediatric patients had been treated with PBT overseas since the programme began. The total number of patients treated overseas in the first seven months of this financial year is 49 and we expect to treat 80 by the end of the financial year. The number is set to increase to 250 in 2012/13, but this needs to be carefully managed as the capacity at overseas centres is limited and costs are increasing.

- 4.8 The National Specialised Commissioning Team Proton Overseas Programme is unusual, if not unique, in the world in using an evidence based and prioritised approach and applying it in a systematic way to a whole population for proton therapy. It is becoming clear that because of this, the NHS will soon have the opportunity to report outcomes on a series of paediatric cancers that match or exceed any in the world literature. A project has started to evaluate the outcomes from the Overseas Programme. Subject to the approval of the business case to build a UK service, the extension of the diagnostic criteria to include a wider range of highly prioritised cases for treatment in the NHS will ensure the NHS can match the best radiotherapy services in the world.

Access to cancer drugs

- 4.9 The Coalition Agreement and the White Paper *Equity and Excellence: Liberating the NHS* set out the Government's plans to reform the way that drug companies are paid for NHS medicines, moving to a system of value-based pricing when the existing Pharmaceutical Price Regulation Scheme (PPRS) expires. This will help ensure licensed and effective drugs are available to NHS clinicians and patients at a price to the NHS that reflects the value they bring. As an interim measure, the Government said it would create a new Cancer Drugs Fund, operating from April 2011, which would address some of the most pressing access issues by helping patients to get the cancer drugs their doctors recommend.
- 4.10 In July 2010, the Government announced that £50 million additional funding had been identified in-year to support improved access to cancer drugs in advance of the launch of the Cancer Drugs Fund. The funding, released from savings in the DH's central budgets, was made available to strategic health authorities (SHAs) from 1 October 2010. SHAs set up regional panels of clinicians to make decisions on the most appropriate use of resources and to approve funding requests.
- 4.11 Following a public consultation between October 2010 and January 2011, on plans for its operation, the Cancer Drugs Fund launched on 1 April 2011. Over three years, the Fund will make £200 million available annually to support improved access to cancer drugs.
- 4.12 Between October 2010 and the end of September 2011, this funding has helped over 7,500 cancer patients in England to access additional cancer drugs that can extend or improve life.

- 4.13 The DH is currently considering what adjustments will need to be made to the Cancer Drugs Fund to reflect the planned changes to the structure of the NHS, including the abolition of SHAs and the establishment of the NHS Commissioning Board.
- 4.14 The DH has also begun working towards a new system of pricing for medicines, where the price of the drug will be linked to its assessed value. Initial proposals for value-based pricing were set out in a consultation, published in December 2010. The Government response to the consultation exercise was published on 18 July 2011. It summarises the responses received to the consultation and sets out the Government's views on the key issues raised. The response welcomed the level of engagement in the consultation from a wide range of stakeholders and confirmed that the Government will continue to engage with patients, clinicians, the NHS, taxpayers, industry and other interested parties as work to reform the pricing of medicines progresses.

Finding out more about the quality of life of cancer survivors

- 4.15 The NHS needs information about the issues faced by cancer survivors in order to ensure they commission and provide the right services.
- 4.16 The fourth and final report of the Mastectomy and Breast Reconstruction Audit was published in 2011²⁰. The audit, describing the provision of mastectomy and breast reconstruction services in England, collected outcome data following mastectomy and breast reconstruction surgery but also patient reported data on women's experiences of care. The report contains new evidence from thousands of women confirming the positive effects of breast reconstruction on their quality of life. In particular, this report presents new findings on the impact of different reconstructive techniques and the timing of surgery on the wellbeing of women.
- 4.17 The National Cancer Survivorship Initiative (NCSI) completed a pilot of a Patient Reported Outcomes Measures (PROMs) survey of cancer survivors in summer 2011. The pilot involved 5,000 patients with breast cancer, prostate cancer, bowel cancer and non-hodgkin's lymphoma at one, two, three and five years post cancer diagnosis.

20 www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NHS%20IC%20MBR%202011%20Final%20Interactive%2016-03-11.pdf

- 4.18 The pilot aimed to test the process for identifying and recruiting the sample and the acceptability to patients of completing a questionnaire relating to their health-related quality of life. The final response rate was an encouraging 68% and a full analysis of the results will be published in the New Year. Plans to roll out the survey nationally in 2012 are being developed, fully incorporating lessons learnt from the pilot.

Survivorship

- 4.19 The NCSI has identified a range of service developments which are likely to improve the health and well-being of cancer survivors. These developments may also reduce the overall costs of survivorship care to the NHS. These proposed service developments are now being tested in a range of settings with support from NHS Improvement and Macmillan Cancer Support. Key initiatives being tested include:
- giving patients a record of their treatment and a care plan at the end of primary treatment for cancer
 - inviting patients who have recently completed treatment to Health and Wellbeing Clinics, where they can gain a range of advice and support to help them get back to as normal a life as possible
 - vocational rehabilitation – helping patients who want to return to work to do so
 - supported self-management, with routine hospital follow up being replaced by remote monitoring for those patients who wish to adopt this approach.

Care plans and treatment summaries

- 4.20 Cancer survivors often have ongoing needs following active treatment. Having a needs assessment during and at the end of treatment helps to identify these needs and allows a care plan to be developed to address these issues in partnership with the cancer survivor. A care plan is then “owned by” and supports the cancer survivor after treatment, including:
- planned surveillance and follow-up care
 - the symptoms of a possible recurrence or consequence of treatment
 - signposting to support groups and local services
 - lifestyle improvements, including physical activity and nutrition
 - psychological support
 - work and finance concerns

- how to re-access the healthcare system if necessary, including out of hours support.
- 4.21 A treatment summary template has also been developed to support improved communication between secondary and tertiary care cancer services and primary care. The template is completed at the end of primary treatment by the hospital and sent to the patient's GP with a copy to the patient. Since the template includes the READ codes for the patient's diagnosis and treatment, it allows GPs to update their own computer systems.
- 4.22 The template has been positively evaluated by GPs and oncology clinicians following testing at nine sites in 2010 and was "highly commended" at the 6th Pfizer Excellence in Oncology Awards 2011 for "Best Patient Support Initiative". The template, a summary review and a user guide to aid implementation are available to download from the NCSI website: www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary/

Treatment Summary Record and Survivorship Care Plan The Christie & Great Ormond Street Hospital

The Christie NHS Foundation Trust, Great Ormond Street Hospital and NHS Improvement have worked together to develop, test, implement and evaluate a survivor's treatment summary and care plan, in order to implement its use into routine long-term follow-up care. The care plan is an individualised summary of a clinical record designed to satisfy information requirements and empower survivors and parents with a higher degree of self-management, influencing improved patient experience.

The main focus was on service design and improving communications. This involved bringing new technology and innovative ideas into clinical practice for the benefit of the survivors and their families. This improves patient support, choice and self-management and can potentially benefit their use of NHS services (eg increasing uptake of appropriate follow-up care, improving clinic attendance and reducing "Do Not Attend" rates). The plan should also help the patient identify future signs and symptoms and what to look for in relation to late effects of treatment. The Children & Young People aftercare pathways will be finalised in March 2012.

"My cancer is lymphoma and I've made friends on the Lymphoma Association, who are at hospitals up and down the country and a girl I was speaking to down south really doesn't have a clue what's going to happen in the future, they've kept her in the dark about it, whereas I've got my plan and I can refer to it and I know what to expect or what's normal. I like knowing what's going on, it's my body so I think they're really useful... definitely".

The Christie Foundation Trust, Cancer Patient Survivor

Health and Wellbeing Clinics

- 4.23 The NCSI has piloted 15 Health and Wellbeing clinics for cancer survivors across England, with a vision that everyone who has had a cancer diagnosis and is living with cancer will have access to an innovative Health and Wellbeing Clinic, providing comprehensive and holistic support to enable them to lead as normal a life as possible.
- 4.24 There is a range of evidence to show that a healthy lifestyle after a diagnosis of cancer can impact on outcomes, including mortality. Specialist advice for survivors on physical activity and diet, for example, could influence quality of life and improved overall survival.

- 4.25 Each clinic provided a “one-stop shop” for services and support. Patients benefited from: easy access to a range of services; information on services they were not previously aware of; and an opportunity to meet and hold discussions with other patients and carers. Those attending the clinics reported that the events helped to normalise their experiences, provided support and enabled a focus on the future.
- 4.26 An evaluation report was published in August 2011 which will inform provision of any future clinics going forward. Evidence emerging from the report suggests that patients who attended a clinic where they received supportive information and access to networking reported:
- an increased knowledge of symptoms and treatment options, as well as increased confidence to self-manage their health
 - the ability to manage emotional distress and to take part in social activities
 - a reduced use of health services.

Vocational rehabilitation

- 4.27 Testing in the vocational rehabilitation (VR) pilot sites completed in July 2011. A final report is due to be published early in 2012, to support commissioners and the future development of VR services. The VR Strategy identified five principles key to improving VR services for people affected by cancer:
- early intervention to provide information and support, to encourage self-management and to begin the conversation about remaining at or returning to work
 - a partnership approach between key services such as health, social care and employment services
 - involvement of employers
 - access to specialist services that can resolve the significant barriers to work such as physical limitations, psychological distress and loss of self-esteem and confidence
 - navigation of services in a way that supports self-management and helps instil confidence in rehabilitation services amongst users.

Supported self-management and remote monitoring

- 4.28 NHS Improvement has led seven national prototype sites, working on 13 adult tumour projects to test a whole system approach to care focused on risk stratification and two critical enabling projects: remote monitoring and care coordination. A final report is due to be published in spring 2012, but ongoing measurement will be important to evidence the longer term benefits of this risk stratified model of care.
- 4.29 Various measures are being collected locally and nationally to evidence the benefits of this whole systems approach to care pathways, including:
- the number of prospective outpatient follow-up slots saved, based on the point of the pathway where patients are risk stratified to no further routine follow-up care
 - the number and percentage of patients risk stratified to each of the levels of care within each tumour type
 - the number of unplanned admissions for patients with a known diagnosis of cancer
 - the number of referrals to care and support services (both internal and external).

North Bristol Hospital NHS Trust: Remote Monitoring

Staff in North Bristol Hospital NHS Trust are testing risk stratified pathways of care for breast, prostate and bowel cancer survivors. In their role leading the work on a national solution for remote monitoring, they are developing electronic solutions for treatment summaries and care plans which will be shared with patients and GPs. They are currently looking at options available for a hand held record for cancer patients.

A good range of health and wellbeing courses have been established, especially for psychological support, along with a successful enhanced recovery programme and nurse led follow up clinics. This work will provide evidence to support QIPP. A report on the outcomes of this testing will be available in spring 2012.

Ipswich Hospital NHS Trust: Supported Self-Management

The breast team have implemented all aspects of the risk stratified pathway and now transfer a high proportion of patients to a supported self-management pathway immediately after the end of treatment. The Ipswich team are also testing the prostate pathway and have developed a wide range of support services focusing on enhanced recovery and a health and wellbeing programme to support and empower the patient in order to self-manage. They provide a “five-week moving on programme” which includes information days working in conjunction with social care and local authorities to set up a physical activity referral scheme, to which 50 patients had been referred by October 2011. Health and wellbeing activities have proved successful, including a swimming club for breast cancer patients and care farms providing practical skills (eg growing your own vegetables). Key to the success of this project have been a large volunteer network and an excellent information centre.²⁰

Children and young people

- 4.30 The success of the work being undertaken on survivorship for children and young people (CYP) will be determined by the ability to achieve the following results:
- 100% of CYP cancer survivors having a care plan
 - An overall 20% reduction nationally in inappropriate follow-up appointments
 - reduction in unnecessary emergency admissions
 - reduction in unnecessary in-patient admissions.
- 4.31 Emerging from the initial CYP testing work, four models of care have been identified:
- traditional primary treatment centre aftercare model
 - a shared care model of aftercare between the primary treatment centre and GP/primary care services
 - a nurse led model of care (that may include variations such as a telephone/text message model of aftercare)
 - a self-management model of aftercare.

21 Effective follow up: testing risk stratified pathways (NHS Improvement, May 2011). www.improvement.nhs.uk

- 4.32 A set of CYP patient pathways have been developed along with these models of care, which have been tested along the patient pathway with four prototype test sites throughout 2011. A report bringing all the data and learning from the pathways together²² was launched at the 6th CYP Survivorship National Workshop in October 2011.
- 4.33 All of the evidence gathered from the adult and CYP prototype sites will be used to refine the pathways and to inform the NCSI's recommendations for commissioning cancer services to ensure those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Great Ormond Street Hospital for Children NHS Trust

Transition Care

To support the needs of children and young people emotionally and physically, Great Ormond Street Hospital has evaluated the current transition care offered via a nurse-led transition clinic to cancer survivors. The project focuses on improving the service currently offered and aims to incorporate new ideas and protocols into clinical practice. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences.

Young survivors aged 16 to 18 years are offered a transition clinic appointment to prepare them for future follow up at an adult hospital setting or with their GP in the community. Further information is offered around a range of issues including: late effects, long-term surveillance, maintaining a healthy lifestyle and fertility.

22 *Designing and implementing pathways to benefit patient aftercare: Continuing to build the evidence* (NHS Improvement, October 2011).
www.improvement.nhs.uk

University Hospitals Bristol NHS Foundation Trust

ON TARGET

“Ensure that each teenager and young adult survivor is supported towards the achievement of a life as it would have been lived without the intrusion of cancer, or as *the patient* has decided to recreate it after experiencing and assessing the impact of the diagnosis of cancer and its treatment.”

ON TARGET is a three year programme of work funded by Macmillan Cancer support and supported by Avon Somerset and Wiltshire Cancer Services Network. The programme will assess and address the aftercare needs of teenagers and young adults (TYA) with cancer, developing and evaluating a series of work packages to facilitate and enhance the evolution of a patient’s care from its initial focus on cancer diagnosis and treatment, towards cancer survivorship.

The programme will be offered to patients aged 16 to 24 years with all forms of cancer. Lessons learned from this project will be used to guide the development of aftercare within the South West TYA service and will be offered for national dissemination.

Carers

- 4.34 The NCSI is developing a carer’s pathway to:
- plot the key phases that the carer is likely to support the patient through (ie diagnosis, treatment, aftercare)
 - identify the carer’s support needs
 - outline the key transition points along the pathway when support should be provided.
- 4.35 This work will be informed by Macmillan Cancer Support’s ongoing work to address and support carers’ needs, as well as the emerging data from the survivorship PROMs survey pilot, which is helping highlight the ongoing social care needs of both patients and their carers.

Priorities for the coming year

- 4.36 The NCSI is beginning work on an update to the NCSI Vision document published in 2010. This document will:
- bring together the evidence collected to date across the survivorship agenda
 - present the “care packages” underpinning the risk-stratified models being tested
 - provide key messages for commissioners and other audiences
 - outline priorities for the future.
- 4.37 Other priorities for the coming year include rolling out the survivorship PROMs survey and supporting the spread of IMRT.

5 NHS Outcomes Framework

Domain 3: helping people to recover from episodes of ill health or following injury

Introduction

5.1 As we set out in *Improving Outcomes: A Strategy for Cancer* (IOSC), ensuring that all cancer patients receive the appropriate treatment, delivered to a high quality, is critical to improving cancer outcomes – and the right treatment can also be the most cost effective treatment. While some of the work over the past year has been about promoting quality of treatment, much has also been about promoting productivity as well. There is a major challenge ahead for the NHS to share learning about the scope to make improvements which promote better outcomes while also saving resources.

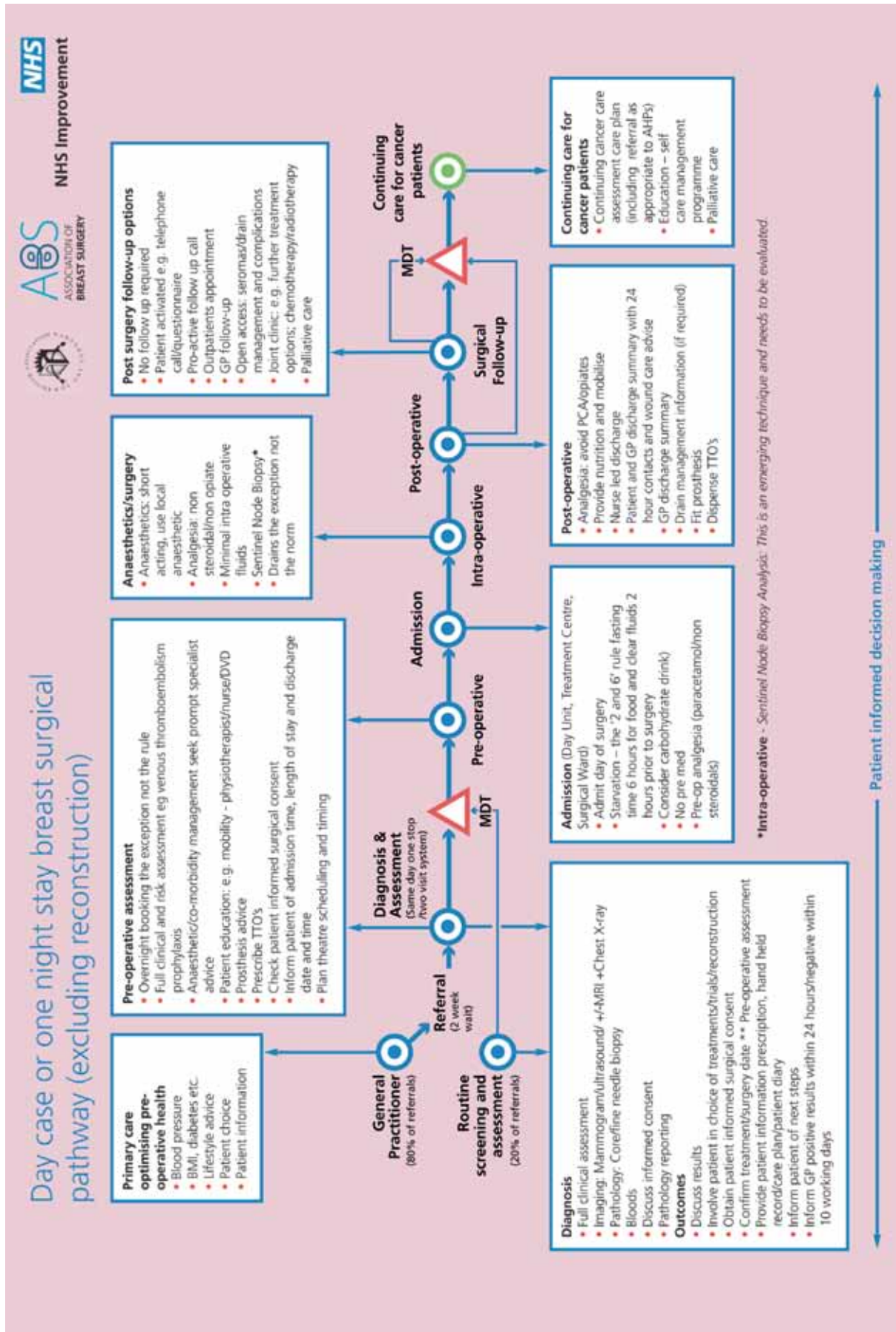
Bed days and emergency admissions

5.2 The National Audit Office report *Delivering the Cancer Reform Strategy*²³ set out the scope to make very significant reductions in bed days and emergency admissions if all PCTs performed at the level of the best quartile.

5.3 Progress continues to be made in reducing bed days. Although we have only provisional data for 2010/11, and the estimates are likely to be revised upwards, the bed days have reduced from 4,719,415 in 2009/10 to 4,469,565 in 2010/11 – despite an increase in episodes of care from 1,251,757 to 1,319,964. The provisional figures in relation to emergency bed days is also positive – with a reduction from 2,889,333 in 2009/10 to a provisional figure of 2,737,624 in 2010/11. However, there is a long way to go to deliver the reductions that the NAO estimated could be achieved, and therefore the productivity improvements needed to fund new cancer services.

23 National Audit Office, *Delivering the Cancer Reform Strategy*, Report by the Comptroller and Auditor General (HC568, Session 2010-2011), November 2011

Figure 5.1. Day case or one night stay breast surgical pathway



Transforming inpatient care programme

- 5.4 NHS Improvement has continued its programme of work to support the NHS to reduce inpatient stays, avoid unnecessary emergency admissions and reduce length of stay when inpatient stays and emergency admissions are necessary.

Elective care

- 5.5 In particular, they have continued to build on progress in promoting the spread and adoption of the breast surgical day case/one night stay pathway across the NHS. Day cases and overnight stays combined now make up 72% of all procedures compared to 47% in 2006/07²⁴. This number continues to increase, indicating that 85% is achievable. Some NHS Trusts have already attained this, exceeding the original working hypothesis of 80%.
- 5.6 Breast cancer bed days have reduced by 50,329 (41%), and the proportion of patients not being admitted the day before surgery has increased from 69.6% in 2006/07 to 94.6%. Patient feedback of their experience of the pathway is extremely positive, and strong clinical engagement is evident in leading the improvements.
- 5.7 However, there are major variations between Trusts in the proportion of patients who have a length of stay (LOS) of more than one night. Against the national average of 28%, 22 Trusts have less than 14% of their patients having LOS of more than one night. 26 Trusts still have 40% or more of their patients having LOS of more than one night and this is where efforts should be concentrated in the coming year.
- 5.8 NHS Improvement has begun to test the model's transferability to other surgical procedures and interventions, with the aim to continue to reduce length of stay and unnecessary bed days. Testing transferability will identify what can be achieved and the levels of ambition. They continue to promote the spread and adoption of the enhanced recovery principles and aim to reduce the national mean length of stay by 10% across six cancer procedures: cystectomy, prostatectomy, colectomy, rectum, abdominal and vaginal hysterectomy.

24 NHS Improvement, *Delivering major breast surgery safely as a day case or one night stay* (December 2011)

- 5.9 NHS Improvement plan to support colorectal, gynaecology and urology (for cystectomy and prostatectomy) teams to have implemented enhanced recovery in 50% of Trusts over the next three years.
- 5.10 The aim is to reduce the national mean length of stay in a number of procedures, including colectomy and prostatectomy, by 10%, leading to a saving of 38,700 cancer bed-days, and increase national day surgery admissions by 10% which will equate to a saving of 6,300 cancer bed-days. This is from a 2010/11 baseline and will be achieved over three years.
- 5.11 The National Cancer Action Team have ensured that regular benchmarking data on enhanced recovery (ER) metrics and an enhanced recovery toolkit for local audit of ER implementation continue to be available within the NHS. Brief guidance for commissioners on ER pathways has also been produced and is available at: www.improvement.nhs.uk/enhancedrecovery/

Emergency admissions

- 5.12 NHS Improvement has been working with Trusts to try and reduce the number of cancer patients presenting as emergencies. One model is communication alerts as shown in the examples.

Key-worker Alerts at Sandwell & West Birmingham Hospitals (SWBH) releases 3,500 bed days Inpatient Management System (IMP)

Patients admitted as an emergency on the system generate an e-mail and a text message to the key worker. Beginning with one tumour group on one hospital site, the key-worker alert has spread to the second hospital site and other tumour groups, including colorectal, upper GI, lung, urology and gynaecology. This has led to reductions in emergency admissions length of stay (LOS) as follows:

- colorectal and upper GI released 3,500 bed days, saving potentially £900,000
- mean LOS for colorectal patients reduced from 20 days to 4 days
- Clinical Nurse Specialist (CNS) saw 87% of patients
- colorectal re-admission rate dropped from 28% to 8%
- upper GI mean LOS reduced from 14 days to 4 days.

Pan Trust Approach — Imperial College Healthcare NHS Trust

Utilising a third party software system – Communication alerts implemented in eight tumour groups and palliative care using a third party software company across three hospital sites: Charing Cross Hospital, Hammersmith Hospital and St Mary's Hospital. The system has been in place for two and a half years and was initially piloted at Charing Cross Hospital in lung and urology. The alerts are sent out to all Clinical Nurse Specialists for each of the tumour groups using mobile phones. Plans are in place to roll-out to all long term conditions, infection control, surgical readmissions and linking systems to other hospitals.

By reducing LOS the Trust has a potential saving of £28,600 in bed days just for unscheduled lung cancer patients alone over one year (130 days saved charged at £200 per day). The system was initially funded by the North West London Cancer Network and a service improvement facilitator was seconded to the hospital Trust to work collaboratively with the network and the hospital Trust.

Improving the quality of surgery

Surgical training programmes

- 5.13 Nationally there has been an increase in the adoption of laparoscopic colorectal surgery during the past year. Provisional HES analysis for 2010/11 show that 34% of all elective resections were undertaken laparoscopically, an increase from 30% in 2009/10. Twenty five Trusts are reporting low levels of laparoscopic surgery (less than 20% of resections). This is a substantial improvement from 2009/10 when 43 Trusts were reporting at this level.
- 5.14 The national training programme for laparoscopic surgery (LAPCO) provides training for colorectal consultants in England and has now signed off 26 trainees. A further 32 trainees are in the sign-off process and 91 are currently in training. To ensure the highest quality of training LAPCO has developed a successful train the trainer course which 41 of the 60 trainers have attended or are registered to attend this year. The programme is also carefully audited to ensure the training is both safe and effective for patients. The priority for the programme is to ensure that all registered trainees progress through their training and reach the requirements to achieve sign off.
- 5.15 The Low Rectal Cancer Development Programme (LOREC) aims to improve cancer outcomes and quality of life for patients with low rectal

cancers. During 2010/11 28 colorectal multi-disciplinary teams (MDTs) from across all cancer networks in England have taken part in the pilot of the low rectal programme. The workshops help MDTs to improve the decisions they make on low rectal cancer patients. They involve surgeons, radiologists, pathologists, oncologists and nurse specialists.

- 5.16 The programme also provides training in a different method of excision of low rectal cancers, the extra levator abdominoperineal excision (eLAPE). This has been shown to substantially reduce circumferential resection margin (CRM) involvement and perforation. Training has been provided to two surgeons from each of the 28 MDTs in this technique. The pilot has been very well evaluated by teams that have attended and so this programme has been extended to a further 28 teams across England.

Robotic prostatectomy framework

- 5.17 In the future, the NHS Commissioning Board (rather than the DH) will issue guidance to local commissioners that will set out how they should achieve improved outcomes for patients through commissioning services that are better quality, more efficient and fairer. This guidance will be based on NICE Quality Standards and other accredited evidence of what works best, including guidance from royal colleges, specialist societies and other professional bodies. The British Association of Urological Surgeons (BAUS) are developing a robotic prostatectomy framework, which will supplement NICE's guidance, which they hope to publish shortly. Commissioners might like to refer to this framework in advance of any formal guidance from the NHS Commissioning Board.

Improving the effectiveness of chemotherapy

- 5.18 In IOSC we said that we would develop a commissioning and funding structure to enable the efficient delivery of high quality molecular diagnostic testing through centres of excellence. We have been working with a group of experts to develop the right mechanisms to ensure patients have rapid access to any new genetic testing of cancers as it becomes available. The arrangements have yet to be finalised but we remain committed to funding cost-effective testing that has strong clinical evidence to support it.

Peer review

- 5.19 The National Cancer Peer Review report for 2010/11 was published on 30 November 2011. It reported overall improvement in cancer services performance against The Manual for Cancer Services during 2010/11,

with 34% of MDTs gaining compliance of over 90% against the peer review measures.

- 5.20 However, a relatively small number of teams (around 1%) are performing poorly, with compliance scores below 50%. A high proportion of these teams also had immediate risks or serious concerns noted by reviewers. These were immediately reported to Trust Chief Executives and have in the majority of cases been resolved.
- 5.21 Across England as a whole similar issues were identified to those in 2009/10: gaps in core team membership and capacity; some complex surgery being undertaken outside of specialist centres, particularly in urology; and the need to strengthen pathways for testicular, penile and hepatobiliary services.
- 5.22 However, there has been progress from 2009/10, with some networks noting an increased complement of CNS, oncology and thoracic surgery input. Peer Review teams reported a great deal of good practice, frequently noting the dedication of the workforce.

Priorities for the coming year

- 5.23 This chapter highlights some of the approaches that Trusts can adopt not only to improve outcomes for their patients, but also to make major savings by reducing inpatient bed days, therefore contributing to the Quality, Innovation, Productivity and Prevention agenda. Trusts will want to look at appropriate options based on analysis of their local circumstances. NHS Improvement will continue to support this work in 2012, and are also looking at what other approaches might be helpful.

6 NHS Outcomes Framework

Domain 4: improving experience of care

Introduction

- 6.1 We are fortunate in the cancer world to have good data about patient experience of care, which provides us with excellent material about the priority issues to be tackled, and which Trusts can use to prioritise local action to improve patient experience. We know from feedback over the last year that many Trusts around the country have taken the problems identified in the 2010 patient experience survey very seriously, and have action plans in place to make improvements. This chapter reports on a range of work under way to help promote better patient experience, and then sets out our priorities for the year ahead.

Patient experience surveys

Cancer patient experience survey 2010

- 6.2 The national report of the 2010 cancer patient experience survey was published in December 2010 and outlined in *Improving Outcomes – a Strategy for Cancer*. Since then 158 bespoke Trust level reports have been published, and the survey provider Quality Health has visited the 10% worst performing Trusts to explain their results and offer practical help on actions to improve the experience of their patients. The survey is clearly having an impact locally, unlike the 2000 survey. For example, the London cancer networks have produced an action plan to improve experience in London hospitals, and every Trust in London has produced their own action plan. A key part of disseminating the 2010 results has been benchmarking, as shown in the figure below, with Trusts in the top 20% on a specific item shaded green and those in the bottom 20% shaded red. The difference is striking. The challenge now is for the “red” Trusts to improve their performance.

6.3 Through the National Cancer Equality Initiative (NCEI), the 2010 survey data has been analysed by equality group. Evidence was found for many differences, for example:

- patients aged 76 and over were less likely to be given the name of a Clinical Nurse Specialist (CNS)
- black and minority ethnic (BME) patients were more likely to report not receiving understandable answers to their questions
- patients from more disadvantaged areas were more likely to report delayed diagnosis
- lesbian, gay and bisexual patients were less likely to report being treated with dignity and respect
- patients with mental health conditions and/or a learning disability were more likely to feel treated as “a set of cancer symptoms”
- women were less likely to feel they were treated with respect and dignity and given sufficient privacy
- men were less likely to be given a name of a CNS who would be in charge of their care.

6.4 These findings, along with many others, have been shared with cancer networks, along with suggestions for action to reduce these differences in reported experience. Multi-variant analysis of the data is also required. To increase the power of the data, once we have the results of the 2011 survey we will combine it with the 2010 survey data to analyse it by equality group to help further identify and understand differences.

Cancer patient experience survey 2011

6.5 The 2011 survey will cover inpatient and day case patients over the period 1 September 2011 to 30 November 2011. Trusts will identify eligible patients in December 2011 and questionnaires are likely to be sent out towards the end of January 2012. We expect the national and Trust level reports to be published in June 2012.

Cancer symptoms survey

6.6 In line with our work to achieve earlier diagnosis of cancer we are supporting a survey co-funded by Cancer Research UK and the National Cancer Action Team (NCAT) to examine the nature and duration of symptoms experienced by people with cancer before their diagnosis.

- 6.7 The survey will be conducted on a sample drawn from the 83% of people who responded to the national cancer patient experience survey 2010 and agreed that they could be contacted again. A postal questionnaire will be sent to approximately 2,500 people who were diagnosed with one of 22 cancer types. The findings of this survey will be available in spring 2012 and will help us to assess the nature of symptoms experienced by cancer patients before their diagnosis and measure the interval between the onset of symptoms and patients first seeking medical advice.
- 6.8 This project is a unique opportunity to add to the limited evidence base on the frequency and duration of symptoms among patients diagnosed with cancer and the time interval between noticing these symptoms and presenting to the health service.

Work to improve patient experience

Information Prescriptions

- 6.9 Fifteen acute Trusts across 34 hospital sites commenced as Information Prescription (IP) beacon sites at the beginning of December 2010, working with 15 Macmillan Cancer IP Facilitators and 203 multi-disciplinary teams (MDTs) and clinical services. Implementation at the beacon sites was completed at the end of August 2011 with over 2,000 staff trained in the use of the IPs and over half of the MDTs routinely issuing IPs to their patients.
- 6.10 Successes have included:
- helping to raise the profile of the importance of written information in the delivery of cancer care
 - enabling clinical teams to develop and test flexible models of patient information delivery
 - increasing partnership working amongst health care professionals
 - high levels of engagement, ownership and input, especially from CNSs.
- 6.11 Challenges have included:
- engagement
 - obtaining ownership and Trust staff taking responsibility
 - changes within the work programme and delayed timescales

- ensuring the technical stability and fitness for purpose of the IP system on NHS Choices.
- 6.12 There is evidence of benefits to patients, including:
- a high level of support and engagement from patient involvement and support groups who report feeling empowered by the concept of IPs
 - access in a single portal to high quality information to support patient care
 - better personalisation and tailoring of information.
- 6.13 The key learning and best practice from the beacon sites have culminated in the development and publication of a national IP Toolkit. A further 34 Trusts have now started work on implementation of IPs, supported by the national programme led by NCAT, Cancer Research UK and Macmillan Cancer Support.

Connected

- 6.14 Communication between clinician and patient remains a key issue and is reflected in the results of the cancer patient experience survey. Since the start of the *Connected* national advanced communication skills training programme over 12,000 senior clinicians have been trained. Funding has also supported training of a wider clinical group within end of life care and other specific clinical areas such as cardiac and renal.
- 6.15 There has been considerable improvement in the patient experience of communication with an overall increase in satisfaction from 63% in 2000 to 82% in 2010. At a national level, priority is being given to training core members of MDTs. Providers can fund other staff to attend if they so wish.

Multi-disciplinary teams – feedback for improving team working (MDT-FIT)

- 6.16 An assessment and feedback tool has been developed to support cancer MDTs to work effectively. The tool, known as MDT-FIT, has been piloted with 26 cancer MDTs, resulting in a range of quality improvements. Further development work is planned to enable the tool to be made available to the wider NHS by January 2013.

Holistic needs assessment

- 6.17 A practical guide for healthcare professionals undertaking holistic needs assessment for people with cancer was issued in March 2011. Further implementation of holistic needs assessment in day to day practice will enable patients to receive more personalised care. Healthcare teams can use holistic needs assessment as a basis for risk stratification to target support and care efforts.

Quality in nursing

- 6.18 Building on the success and publication of the 2010 adult CNS census report, the census is being repeated in 2011 to align with the cancer patient experience survey to enable direct comparisons to be made between the results relating to CNS presence and patient satisfaction. Work is also underway to analyse the results from the 2010 survey to identify and widely disseminate actions associated with high performing Trusts.
- 6.19 A series of case studies have been produced to align with the DH Nursing Career Framework, and the cancer version of the framework will be used to attract new nurses into oncology and aid the career development of the existing cancer nursing workforce. Indicators on symptom experience and supportive care developed as part of the nurse sensitive outcome measures (NSOMs) in ambulatory chemotherapy work are being used to develop a PROM for chemotherapy which will be available in early 2012.

BME patient experience work programme

- 6.20 The BME Cancer Voice was established to understand the issues facing people from BME communities who have been affected by cancer. The 2010 cancer patient experience survey highlighted the variation in the views of patients from BME communities compared to white cancer patients. A number of surveys have been developed to understand further the reasons for the poor perception of care, with the aim of working towards improvements.
- 6.21 Qualitative based research has also been undertaken with a number of Trusts which followed up the 2009/10 culturally sensitive baseline audit²⁵. The research has been carried out in partnership with Breast Cancer Care, and has been focused on finding where best practice already exists in

25 Analysis of the National Black and Minority Ethnic (BME) Baseline Audit (Picker Europe Ltd for the National Cancer Action Team – NCAT, Spring 2010).
www.cancerinfo.nhs.uk/images/stories/ncip_bmeaudit_june_10.pdf

providing culturally diverse cancer services. A report aimed at commissioners and providers will be available early in 2012.

Macmillan values-based principles

- 6.22 Under the umbrella of the NCEI, and in partnership with cancer service providers, Macmillan Cancer Support has developed proposals for changes based on human rights principles which are expressed as visible behaviours. The values-based principles have eight behaviours or “moments that matter” to patients that can be used as indicators of service quality and which have been developed using a bottom up methodology in partnership with patients, carers and professionals:
- Naming – “I am the expert on me”
 - Private communication – “My business is *my* business”
 - Communicating with more sensitivity – “I’m more than my condition”
 - Clinical treatment and decision-making – “No decision about me, without me”
 - Acknowledge me if I am in urgent need of support – “I’d like not to be ignored”
 - Control over my personal space and environment – “I’d like to feel comfortable”
 - Managing on my own – “I don’t want to feel alone in this”
 - Getting care right – “My concerns can be acted upon”.
- 6.23 Macmillan will now work with participating Trusts to align use of the values-based principles with work to improve patient experience.

End of life care

- 6.24 The third annual report on implementation of the End of Life Care Strategy was published by the DH in September 2011. The report highlights a wide range of work that has been undertaken, and which is currently underway to support improved care for people approaching the end of life, regardless of their condition.

Indicator – Proportion of deaths in usual place of residence

- 6.25 The Vital Sign for end of life care, which recorded progress on deaths at home, has been replaced with a supporting measure in the new performance management system. The new indicator covers both

people's own homes and care homes, in response to feedback that once someone had moved into a care home this in effect became their home.

- 6.26 There has been a continuation in the slow trend towards increasing the percentage of deaths which take place in the community and reducing the percentage of all deaths which take place in hospital. 2010 figures show that 39.3% of all deaths occurred in someone's usual place of residence (20.8% at home, 18.5% in a care home) 53.3% in hospital and 5.3% in hospices.
- 6.27 The Quality, Innovation, Productivity and Prevention (QIPP) end of life care workstream has adopted the deaths in usual place of residence (DIUPR) indicator as a reflection of both quality and productivity. QIPP will also be adopting new indicators to capture the quality and effectiveness of services in responding to people's needs and wishes at the end of life. These are currently in development.

Survey of bereaved people

- 6.28 Delivering on a commitment in the End of Life Care Strategy, a pilot was undertaken by the University of Southampton to revise and test out a new version of VOICES (Views Of Informal Carers – Evaluation of Services), and how this could be used in a national survey of bereaved people. Following completion of the pilot, a national survey of the bereaved has now been commissioned. The survey is being managed by the Office for National Statistics, and it is due to complete in March 2012.
- 6.29 The national survey will allow us, for the first time, to compare the quality of the experience of care at the end of life across different conditions, different care settings and different geographies. It will give feedback for the first time on the family and carer experience as well as the patient's. It will be the data source for the new national indicator for end of life care in Domain 4 of the NHS Outcomes Framework. The indicator is currently going through the DH's development process.

Palliative Care Funding Review

- 6.30 In the Coalition Programme and the White Paper *Equity and Excellence: Liberating the NHS*, the Government set out its commitment to develop a per-patient funding system for palliative care.
- 6.31 To make this a reality, in July 2010 Thomas Hughes-Hallett, Chief Executive of Marie Curie Cancer Care, agreed to chair an independent review of dedicated palliative care funding. As the review covered both

adults' and children's services Professor Sir Alan Craft, a former President of the Royal College of Paediatrics and Child Health, provided input and expertise on the children's side.

- 6.32 The review's final report was published on 1 July 2011. It set out a proposed funding mechanism for palliative care across all sectors, with recommendations for those areas that a per-patient tariff should fund, and those areas that should be excluded. A key finding of the review was the "stunning lack of good data surrounding costs for palliative care in England"²⁶. This led the review panel to propose extensive piloting to inform the development of currencies and a tariff to underpin the proposed new system.
- 6.33 Ministers are currently considering the recommendations, but have agreed with the review about the need to develop a strong evidence base. The DH has therefore issued a call for expressions of interest from organisations interested in being pilot sites. Piloting is due to begin in April 2012.

Priorities for the coming year

- 6.34 The 2011 cancer patient experience survey will show whether improvements in patients' experience occurred between early 2010 and late 2011. However, it can be anticipated that more work will need to be done to bring the quality of care provided by all teams up to the level of the best. The national programmes of work identified in this chapter will continue to support local clinicians and teams to improve care delivery.

26 Palliative Care Funding Review: Funding the Right Care and Support for Everyone: Tom-Hughes-Hallet et al, July 2011

7 NHS Outcomes Framework

Domain 5: treating and caring for people in a safe environment and protecting them from avoidable harm

Introduction

7.1 Commissioners, providers and patients need to be assured that local cancer services are safe. However, until this year no routine data on cancer patient safety has been available at NHS Trust level on which reliable comparisons can be made. A major step forward was made in April 2011 with the publication in *Gut* of casemix-adjusted 30-day mortality data for all colorectal cancer surgery services in England²⁷.

30-day mortality for colorectal surgery

7.2 This publication showed that overall 30-day mortality was 6.7%, but it decreased over time from 6.8% in 1998 to 5.8% in 2006. The largest reduction in mortality was seen in 2006. Post-operative mortality increased with age, co-morbidity, stage of disease, socio-economic deprivation and operative urgency.

7.3 Risk-adjusted control charts showed that one Trust had consistently better outcomes and three had significantly worse outcomes than the population mean.

7.4 The funnel charts below show the differences between 1998/2002 and 2003/2006.

27 *Thirty-day postoperative mortality after colorectal cancer surgery in England*, Morris et al, *Gut* doi:10.1136/gut.2010.232181
<http://gut.bmj.com/content/early/2011/03/08/gut.2010.232181.abstract>

Figure 7.1. Risk-adjusted 30-day mortality (%) (adjusted for sex, age, year of diagnosis, cancer site, deprivation, Dukes' stage, Charlson co-morbidity score and resection type), by NHS Trust, for colorectal cancer patients who underwent major resection: England, patients diagnosed 1998–2002

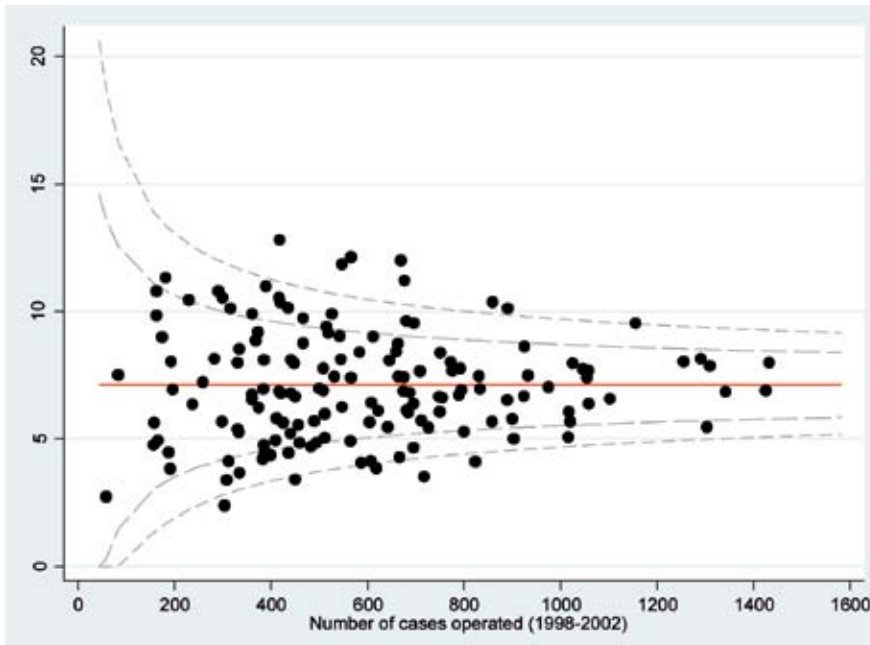
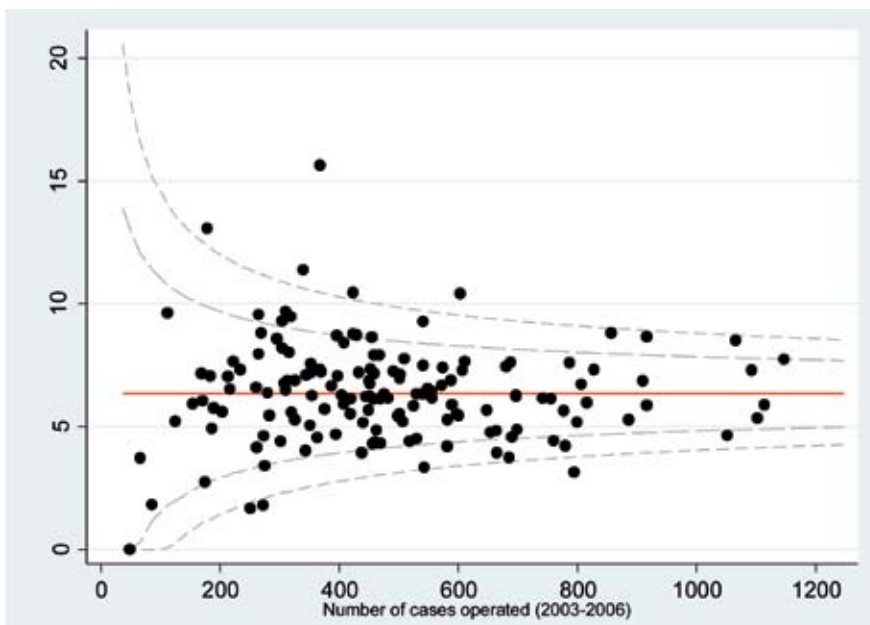


Figure 7.2. Risk-adjusted 30-day mortality (%) (adjusted for sex, age, year of diagnosis, cancer site, deprivation, Dukes' stage, Charlson co-morbidity score and resection type), by NHS Trust, for colorectal cancer patients who underwent major resection: England, patients diagnosed 2003–2006



- 7.5 A subsequent analysis for the National Cancer Intelligence Network (NCIN) for 2007 and 2008 indicates that the Trusts which were outside the outer limits on the control chart in 2002/06 were not within these limits.

Appropriateness of radiotherapy

- 7.6 Data from the radiotherapy dataset can potentially be linked with information from cancer registries on outcomes, to provide data on mortality within defined time periods after radiotherapy. The National Radiotherapy Implementation Group will be asked to advise on appropriate metrics both for radical and palliative treatment.

Safety following chemotherapy

- 7.7 The report published by the National Confidential Enquiry into Patient Outcomes and Death in November 2008 highlighted the problem of patients dying within 30 days of receiving chemotherapy. In response to this, the National Chemotherapy Advisory Group published a report in 2009 recommending that all Trusts with emergency departments should establish an Acute Oncology Service.
- 7.8 Good progress is being made. This has been demonstrated by a recent snap shot survey of almost 90 Trusts and from findings of the peer review programme. New consultants and nurses have been appointed, demonstrating that lack of resources is not the issue preventing further implementation. There remain challenges but we are confident that these can be overcome.
- 7.9 Every cancer network has reported changes in practice to comply with the Acute Oncology Peer Review measures. This includes network-wide campaigns addressing febrile neutropenia and working with colleagues in A&E departments and primary care to recognise early symptoms and commence treatment within an hour. Many Trusts are using oncology nurse-staffed triage bays and helplines based on a tool developed by the UK Oncology Nursing Society to enable patients with complications to be assessed more quickly. This has resulted in reduced length of stay and/or admission avoidance.



The FACTS Campaign (Fast Access to Cancer Treatment Support) has been developed across Lancashire and South Cumbria Cancer Network to raise awareness for patients and healthcare professionals of the signs and symptoms that require prompt action so as to reduce oncology emergencies.

The awareness message is being delivered in a number of different ways:

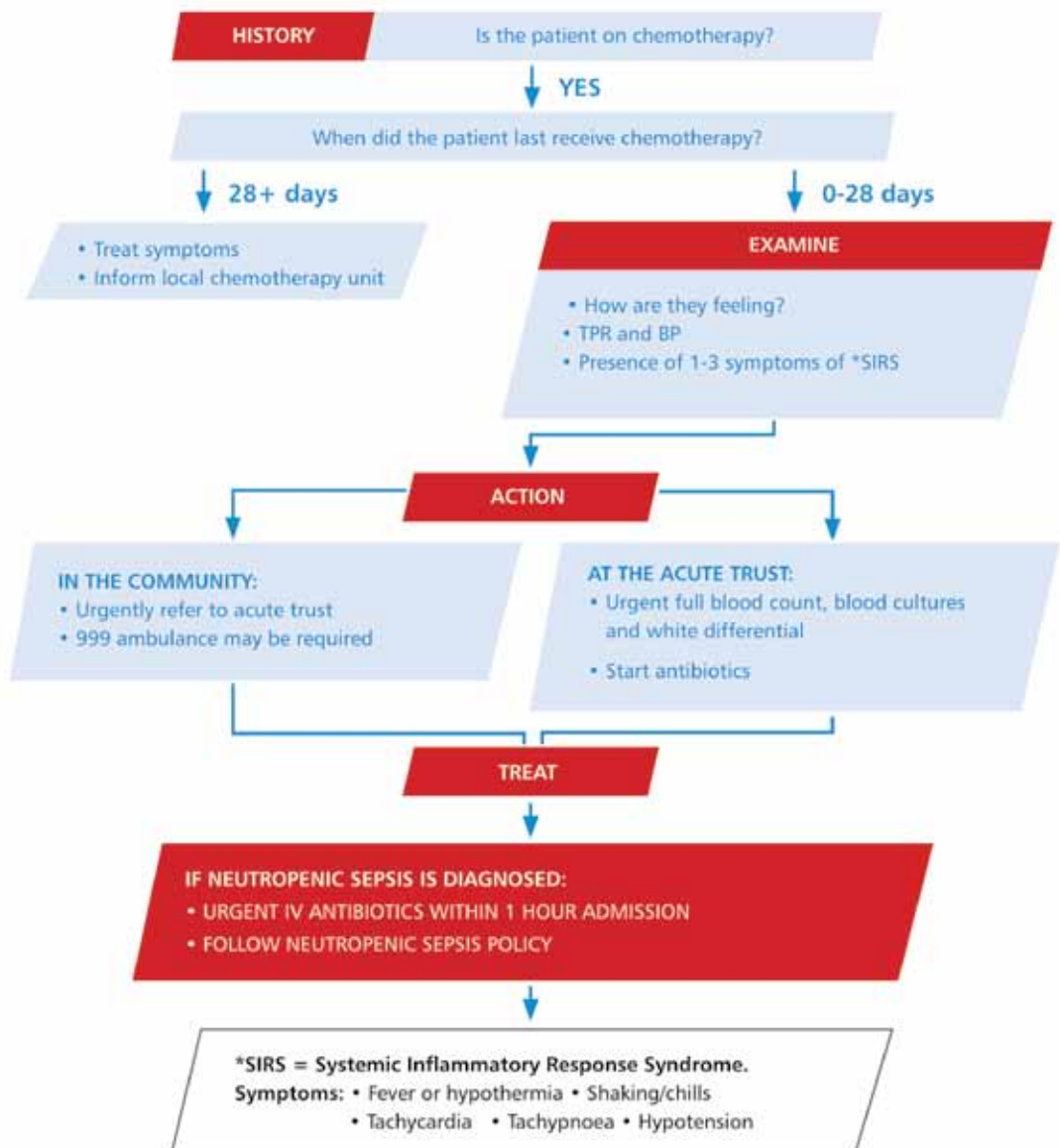
- FACTS folders for professionals containing information sheets about neutropenic sepsis, metastatic spinal cord compression (MSCC), superior vena cava obstruction (SVCO) and the Oncology/Haematology Helpline Assessment Tool
- FACTS eLearning resources for professionals, hosted on local intranets on the Northwest LMS and the FACTS website)
- FACTS folders for patients which include a system alert card
- FACTS pre-Chemotherapy DVD for patients.

There is a FACTS website www.factsoncancertreatment.org which will contain links to the above resources.



Management of Neutropenic Sepsis*

Remember, Neutropenic Sepsis can be **FATAL**. Symptoms may be vague and often there is no obvious focus of infection.



*This information is based on the Sussex Cancer Network's Heat assessment tool.

Priorities for the coming year

- 7.10 By March 2012, NCIN Site Specific Clinical Reference Groups are planning to update national 30-day post-operative mortality analyses for colorectal cancer – examining rates at both Trust and cancer network level – and also to carry out similar analyses for some other cancers. We hope that this will be the first of a range of analyses that helps inform commissioners, providers and patients about safety in the future. We will also continue to support the development of Acute Oncology Services.

8 Delivering change

Introduction

- 8.1 Several different levers and mechanisms are now available to support improvements in quality and productivity at a local level. These include:
- support for commissioning
 - publication of comparative information or “profiles” and other intelligence
 - guidance and Quality Standards developed by the National Institute for Health and Clinical Excellence (NICE)
 - tariffs – including best practice tariffs
 - clinical networks and developing clinical senates
 - national support for service improvement through National Cancer Action Team (NCAT) and NHS Improvement.

Support for commissioning

- 8.2 The NCAT has been working with cancer networks and with the leaders of emerging clinical commissioning groups to assess what support they would find most useful in relation to commissioning cancer services in the future. Two strong messages have come through from this engagement exercise. First, commissioners want to have easy access to comparative data, so that they can assess which aspects of cancer service delivery require the most urgent attention. Secondly, they want to be given key messages on national priorities in an accessible form.

Publication of comparative information or “profiles”

- 8.3 A major focus of activity for the National Cancer Intelligence Network during 2011 has been the development and publication of comparative information or “profiles”. These have included:
- GP practice profiles – allowing GP practices to compare their cancer-related activity with that of other practices within their PCT and across England. Data items include screening coverage and usage of the two-week wait urgent referral route

- commissioner profiles – allowing PCTs and, in the future, subject to the passage of the Health and Social Care Bill, clinical commissioning groups to compare their performance with others, for example with respect to one-year survival rates from March 2012
- service profiles – which will bring together a wide range of information on the activity and performance of individual cancer teams and services across the country.

Key messages for commissioners

- 8.4 In conjunction with commissioners, cancer networks and other key stakeholders, we have developed key messages for commissioners for cancer services. These set out, in a brief and accessible format, key issues and information for cancer commissioners, eg about the scope for improving quality and productivity through new approaches to inpatient care. These messages are being disseminated via cancer networks.

NICE Quality Standards

- 8.5 The NICE breast cancer quality standard was published in October 2011²⁸. NICE quality standards for bowel, lung and ovarian cancer are in development. The NICE prostate cancer quality standard is being developed as part of the review of the NICE prostate cancer clinical guideline.

Tariffs

- 8.6 Work has been continuing to promote better coding, recording and costing of chemotherapy and radiotherapy. The DH plans to mandate the use of national currencies for radiotherapy and chemotherapy for 2012/13 and will be publishing non-mandatory prices for both areas.
- 8.7 Having reviewed all drugs on the OPCS list to ensure that the version released by Connecting for Health in April 2011 included all new regimens, NCAT is again working on this for 2012 when the new list will have in excess of 800 regimens on it. We are now working to develop a longer term strategy for the maintenance of the national regimen list.

28 NICE Breast cancer quality standard, October 2011.
www.nice.org.uk/guidance/qualitystandards/breastcancer/home.jsp

Commissioning Outcomes Framework

- 8.8 The NHS Outcomes Framework sets out national outcomes goals for the NHS, including on cancer. Subject to the passage of the Health and Social Care Bill, the Board will translate these into outcomes and indicators that are meaningful at local level in the Commissioning Outcomes Framework. The Board is engaging with clinical commissioning groups, patient and professional organisations to develop emerging proposals for the Commissioning Outcomes Framework. A document setting out the proposed approach to how the Commissioning Outcomes Framework will work has been published on the NHS Commissioning Board's website²⁹.
- 8.9 The Board will use the Commissioning Outcomes Framework to drive local improvements in quality and outcomes for patients, to hold clinical commissioning groups to account, so that there is clear, publicly available information on the quality of healthcare services commissioned by commissioning groups and progress in reducing health inequalities.

Clinical networks and senates

- 8.10 The Government accepted the NHS Future Forum's recommendations earlier in 2011 to strengthen and embed clinical networks in the NHS, and to establish new clinical senates. A group has been set up to develop proposals for clinical networks and senates in the new system.
- 8.11 Clinical networks already exist and although they can take many forms, they are usually specific to a client group, disease group or professional group. They can undertake a range of functions, including supporting improvements in pathways and outcomes of care.
- 8.12 Clinical senates are intended to bring together a range of experts, professionals and others from across different areas of health and social care to provide cross-cutting advice on strategic commissioning decisions for broad geographical areas of the country.

Clinical networks

- 8.13 In May 2011, the Government announced that it would fund and support cancer networks in 2012/13, and that the NHS Commissioning Board will continue to support strengthened cancer networks – and a range of other networks – thereafter, as a means of bringing the clinical expertise and clinical commissioning responsibilities together, continuously to improve outcomes for cancer patients.

29 www.commissioningboard.nhs.uk

- 8.14 In the listening events carried out as part of the Future Forum's work, there was widespread support for both the principle of networks and their operation in many areas, but also concerns about variations in effectiveness. As a result, a group has been set up to review the range, function and effectiveness of current clinical networks. This work will: map the current patterns of networks and assess the current level of resource associated with them; define what is meant by "network" and the role of potential models in the new system; and propose which clinical and professional areas require formal networks. This work is expected to lead to a suggested operating model, or a set of operating models for networks, which the NHS Commissioning Board Special Health Authority will consider.

Clinical senates

- 8.15 Clinical senates are expected to be a way of bringing clinical leaders together across broad areas of the country to provide a vehicle for cross speciality collaboration, strategic advice and innovation to support commissioners. They will have an enabling role for both clinical commissioning groups and the NHS Commissioning Board, but they will not be new statutory bodies or formal organisations.

Major new research projects

- 8.16 During 2011, several important research studies have been published which are already informing or will inform national policy and clinical practice. These include:
- the International Cancer Benchmarking report on cancer survival in six countries (see chapter 1)
 - a report on projections of cancer incidence to 2030, showing the number of cancers in the UK will grow substantially reflecting the growing and ageing population³⁰
 - a report of a trial of lung cancer screening, showing a mortality benefit from low-dose computed tomography scanning³¹
 - trials of new anti-cancer drugs and of intensity modulated radiotherapy for head and neck cancer

30 Mistry et al, Cancer incidence in the United Kingdom: projections to 2030, *British Journal of Cancer* (2011) **105**, 1795–1803.

www.nature.com/bjc/journal/v105/n11/full/bjc2011430a.html

31 The National Lung Screening Trial Research Team, *Reduced Lung-Cancer Mortality with Low-Dosed Computed Tomographic Screening*, 10.1056/NEJMOa1102873 NEJM.ORG www.nejm.org/doi/full/10.1056/NEJMOa1102873

- a supplement of the British Journal of Cancer specifically related to cancer survivorship research in the UK³²
- a randomised controlled trial from the USA showing that early referral to palliative care services in patients with lung cancer improves quality of life and extends survival.

Priorities for the coming year

- 8.17 In 2012 it will be important to continue the critical work of elements of the National Cancer Programme working with colleagues developing the new bodies to ensure that we do not lose momentum in our ambition to improve outcomes for patients with cancer.

32 The National Cancer Survivorship Initiative: Mew and Emerging Evidence on the Ongoing Needs of Cancer Survivor, British Journal of Cancer, Volume 105, Issue S1(S10S94), 3 November 2011.
www.nature.com/bjc/journal/v105/n1s/index.html

Cancer Service Profiles for Colorectal Cancer - 'Look and feel' mockup - dummy data

Version 0.4, Sept 2011. Please email comments and feedback to profile@nca.gov.uk

NHS National Cancer Action Team Part of the National Cancer Programme

Trust is significantly different from England mean
 Trust is not significantly different than England mean
 Statistical significance can not be assessed
 England mean



Jo Baggis NHS Trust

Select Trust/MDT

Legend: 100% 95% 90% 85% 80% 75% 70% 65% 60% 55% 50% 45% 40% 35% 30% 25% 20% 15% 10% 5% 0% Highest in Eng.

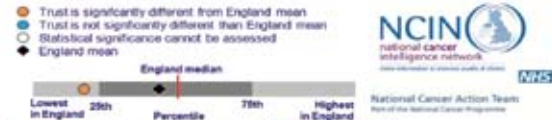
Section	#	Indicator	No. of patients/cases or value	Proportion or rate			Trust rate or proportion compared to England mean		Source	Period		
				Trust	Lower 95% confidence limit	Upper 95% confidence limit	England	Range				
Demographics (based on new patients treated in year)	1	Number of new patients treated per year	95				0%		100%	Cancerwatts	2010	
	2	Patients aged 70+	55	50%	49%	52%	50%	0%		100%	etc	etc
	3	Patients with recorded ethnicity	89	80%	86%	82%	94%	0%		100%		
	4	Patients recorded as non white-British	15	15%	15%	15%	16%	0%		100%		
	5	Patients who are income deprived	Quintile 2	17%	16%	18%	21%	0%		100%		
	6	Male patients	3	2%	2%	2%	6%	0%		100%		
	7	Patients with a registered cancer stage	73	70%	69%	72%	76%	0%		100%		
	8	Patients with a Stage A or B disease at diagnosis	45	40%	39%	41%	44%	0%		100%		
	9	Patients with a Charlson co-morbidity index >0	34	34%	33%	36%	39%	0%		100%		
Specialist Team	10	The specialist team has full membership	Yes				0%		100%			
	11	Proportion of poor review indicators met		82%			0%		100%			
	12	Poor review: are there immediate risks?	No				0%		100%			
	13	Poor review: are there serious concerns	No				0%		100%			
	14	Patients reporting good availability of a CNS	95	92%	89%	95%	98%	0%		100%		
	15	Surgeons not managing 20+ cases per year	4	40%	39%	41%	45%	0%		100%		
Through patient	16	Number of two week wait referrals for cancer	45				0%		100%			
	17	Number and proportion of admissions that are emergencies	129	48%	47%	49%	55%	0%		100%		
	18	Patients referred via the screening service	17	17%	16%	18%	18%	0%		100%		
Waiting times	19	IWW referrals with suspected cancer seen within 2 weeks	35	88%	85%	91%	95%	0%		100%		
	20	IWW referrals treated within 62 days	41	98%	95%	101%	99%	0%		100%		
	21	IWW referrals diagnosed with cancer	7	7%	7%	7%	9%	0%		100%		
	22	Patients treated within 31 days of agreeing treatment plan	91	91%	89%	94%	91%	0%		100%		
Practice	23	Surgical cases treated laparoscopically	15	12%	12%	12%	17%	0%		100%		
	24	Patients resected for liver metastases	8	8%	8%	8%	14%	0%		100%		
	25	Patients undergoing a major surgical resection	29	32%	31%	33%	37%	0%		100%		
	26	Mean length of stay for elective admissions	4.5	4.4	4.6	4.5	0		10	10		
	27	Mean length of stay for emergency admissions	5.7	5.5	5.9	5.7	0		10	10		
Outcomes and Recovery	28	Surgical patients readmitted as an emergency within 28 days	4	4%	4%	4%	9%	0%		100%		
	29	Now to follow up outpatients appointments		75%	74%	76%	79%	0%		100%		
	30	Patients treated surviving at one year	95	90%	87%	93%	95%	0%		100%		
	31	Surgical patients who die within 30 days	1	1%	1%	1%	1%	0%		100%		
Patient Exp.	32	Patients reporting being treated with respect and dignity	95	92%			0%		100%			
	33	Cancer patient experience survey questions scored as 'green'	3	87%			0%		100%			
	34	Cancer patient experience survey questions scored as 'red'	5	4%			0%		100%			

Annex A Examples of Trust service profiles

Cancer Service Profiles for Breast Cancer

Data displayed are for patients for which the trust of treatment can be identified. For a full description of the data and methods please refer to the draft 'Meta-data for profile indicators'. For advice on how to use the profiles and the consultation, please refer to 'Profiles consultation guidance'. Please direct comments/feedback to service.profiles@ncin.org.uk

Example Trust Select Trust/MDT



Section	#	Indicator	No. of patients/cases or value	Percentage or rate			Trust rate or percentage compared to England			Source	Period	
				Trust	Lower 95% confidence limit	Upper 95% confidence limit	England	Lowest	Range			Highest
Size	1	Number of new patients treated per year, 2010-11	322					63		CWT	2010-11	
	2	Number of newly diagnosed patients treated per year, 2009	379					8		CWT/NCDR	2009	
Demographics <small>(based on newly diagnosed patients treated, 2009)</small>	3	Patients aged 70+	111	29%	25%	34%	30%	13%		CWT/NCDR	2009	
	4	Patients with recorded ethnicity	297	78%	74%	82%	91%	73%		CWT/NCDR	2009	
	5	Patients with recorded ethnicity which is not White-British	71	24%	19%	29%	9%	0%		CWT/NCDR	2009	
	6	Patients who are Income Deprived (1)		10%			14%	6%		CWT/NCDR	2009	
	7	Male patients	3	1%	0%	2%	1%	0%		CWT/NCDR	2009	
	8	Patients with a nationally registered Nottingham Prognostic Index (NPI)	216	57%	52%	62%	45%	0%		CWT/NCDR	2009	
	9	Patients with a nationally registered NPI in excellent or good prognostic groups	116	54%	47%	60%	62%	36%		CWT/NCDR	2009	
	10	Patients with Charlson co-morbidity index >0 <small>(to be included in later profile releases)</small>								CWT/NCDR	2009	
	Specialist Team	11	Does the specialist team have full membership? (2)	PR	Yes						NCPR	2010-11
		12	Proportion of peer review indicators met	PR	64%			76%			NCPR	2010-11
13		Peer review: are there immediate risks? (3)	PR	Yes						NCPR	2010-11	
14		Peer review: are there serious concerns? (3)	PR	Yes						NCPR	2010-11	
15		CPES (4): Patients surveyed and % reporting being given name of a CNS (5,6)	120	90%			94%	73%		CPES	2010	
16		Surgeons not managing 30+ cases per year	4	67%	30%	90%	40%	0%		HES	2009-10	
Throughput	17	Number of urgent GP referrals for suspected cancer	1,356					307		CWT	2010-11	
	18	Patients with invasive cancer and treated at this trust	318	99%	97%	100%	92%	52%		CWT	2010-11	
	19	Patients with non-invasive cancer and treated at this trust	4	1%	0%	3%	8%	0%		CWT	2010-11	
	20	Episodes following an emergency admission (new and existing cancers)	396	37%	34%	40%	38%	10%		HES	2009-10	
	21	Patients referred via the screening service	115	30%	26%	35%	33%	0%		VMCIU	2009	
Waiting times	22	Quarter 1: Urgent GP referral for suspected cancer seen within 2 weeks	301	100%	99%	100%	97%	84%		CWT	2011-12 Q1	
	23	Quarter 1: Treatment within 62 days of urgent GP referral for suspected cancer	42	100%	92%	100%	97%	80%		CWT	2011-12 Q1	
	24	Urgent GP referrals for suspected cancer diagnosed with cancer <small>(to be included in later profile releases)</small>								CWT	2010-11	
	25	Cases treated that are urgent GP referrals with suspected cancer								CWT	2010-11	
Practice	26	Quarter 1: First treatment began within 31 days of decision to treat	565	99%	98%	100%	99%	92%		CWT	2011-12 Q1	
	27	Quarter 1: Urgent breast symptom referrals (cancer not suspected) seen in 2 wks	420	98%	96%	99%	95%	48%		CWT	2011-12 Q1	
	28	Surgical cases receiving sentinel lymph node biopsy	75	17%	13%	20%	31%	0%		HES	2010-11	
	29	Day case or one overnight stay surgery	266	66%	61%	70%	71%	28%		HES	2010-11	
	30	Mastectomy patients receiving immediate reconstruction	18	16%	11%	24%	19%	0%		HES	2010-11	
	31	Major surgeries in breast cancer patients (including in-situ cases)	227	60%	55%	65%	74%	50%		HES/NCDR	2009	
	32	Surgical patients receiving mastectomies	119	32%	28%	37%	39%	22%		HES	2010-11	
	33	Mean length of episode for elective admissions		2.5			2.9	0.7		HES	2009-10	
	34	Mean length of episode for emergency admissions		5.0			5.1	2.4		HES	2009-10	
Outcomes and Recovery	35	Surgical patients readmitted as an emergency within 28 days	6	2%	1%	4%	4%	1%		HES	2010-11	
	36	Quarter 2-4: First outpatient appointments of all outpatient appointments	1191	67%	65%	69%	57%	26%		PBR SUS	2010 Q2-Q4	
	37	Patients treated surviving at one year <small>(to be included in later profile releases)</small>										
Patient Experience - CPES (4)	38	Patients surveyed & % reporting always being treated with respect & dignity (5)	120	74%			82%	65%		CPES	2010	
	39	Number of survey questions and % of those questions scoring red and green (7)	59	58%				0%		CPES	2010	
	40			2%				0%		CPES	2010	

Definitions: (1) Based on patient postcode and uses the Index of Multiple Deprivation (IMD) 2010; (2) Peer Review (NCPR) source - IV=Internal Verification, PR= Peer Review, EA= Earned Autonomy; (3) The immediate risks or serious concerns may now have been resolved or have an action plan in place for resolution; (4) CPES = Cancer Patient Experience Survey; (5) CNS = Clinical Nurse Specialist; (6) Italic value = total number of survey respondents for tumour group; (7) Based on scoring method used by the Department of Health - red/green scores given for survey questions where the trust was in the lowest or highest 20% of all trusts. Questions with lower than 20 respondents were not given a score. Italic value displayed = the total number of viable survey questions, used as the denominator to calculate the % of red/green for the trust.

NA = not applicable or not available

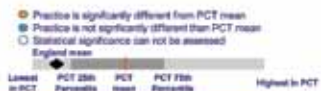


Annex B Example of a GP practice profile

Cancer Indicators in (Y9001) Example Practice, Another PCT (500)

These profiles provide comparative information for benchmarking and reviewing variations at a General Practice level. They are intended to help primary care think about clinical practice and service delivery in cancer care, in particular, early detection and diagnosis. They are not for the purpose of performance management and there are no 'right or wrong' answers. PCT data are based on aggregated practice data and may not be comparable to other sources - see data definitions document.

Practice population (2010/11): 15,821
PCT total practice population: 190,143



Domain	Indicator (Rate or Proportion in brackets)	Practice indicator value	Practice indicator rate or proportion	Lower 95% confidence limit	Upper 95% confidence limit	PCT mean	England mean	Practice rates or proportion in PCT			Source	Period
								Lowest practice	Range	Highest practice		
Demographics	1 Practice Population aged 65+ (% of population in this practice aged 65+)	1,662	15.8%	15.1%	16.5%	12.0%	16.0%	6.4%		22.3%	ADS	April 2010
	2 Socio-economic deprivation, "Quintile 1" = affluent (% of population income deprived)	Quintile 2	10.0%	9.4%	10.6%	8.8%	15.0%	7.0%		11.0%	APHO	2010
	3 New cancer cases (Crude incidence rate: new cases per 100,000 population)	45	437	320	563	321	446	111		703	NCRN/PCQR	2009
	4 Cancer deaths (Crude mortality rate: deaths per 100,000 population)	24	228	146	339	156	234	72		327	PCMD	2010/11
	5 Prevalent cancer cases (% of practice population on practice cancer register)	175	1.7%	1.4%	1.9%	1.3%	1.8%	0.5%		2.4%	QOF	2010/11
Cancer screening	6 Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, %)	751	71.3%	68.5%	74.0%	67.0%	72.5%	47.4%		76.3%	Open Exter	2009/09-2010/11
	7 Females, 50-70, screened for breast cancer within 6 months of invitation (Uptake, %)	719	72.6%	69.7%	75.2%	69.7%	74.7%	26.1%		75.6%	Open Exter	2010/11
	8 Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, %)	2,017	73.8%	72.1%	75.4%	72.1%	75.6%	67.8%		80.4%	Open Exter	2006/06/3-2010/11
	9 Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, %)	449	50.2%	46.9%	53.4%	51.5%	51.5%	33.1%		61.1%	Open Exter	2008/09/3-2010/11
10 Persons, 60-69, screened for bowel cancer within 6 months of invitation (Uptake, %)	245	52.7%	48.1%	57.2%	53.9%	57.5%	36.2%		64.2%	Open Exter	2010/11	
Cancer Waiting Times	11 Two-week wait referrals (Number per 100,000 population)	142	1,350	1,137	1,591	1,380	1,812	657		3,226	CWT	2010/11
	12 Two-week wait referrals (Indirectly age standardised referral rate)	142	75.0%	63.2%	86.4%	n/a	100.0%	36.3%		176.8%	CWT	2010/11
	13 Two-week referrals with cancer (Conversion rate: % of all TWW referrals with cancer)	19	13.4%	8.7%	20.0%	10.0%	10.9%	2.9%		21.7%	CWT	2010/11
	14 Number of new cancer cases treated (% of which are TWW referrals)	54	35.2%	23.8%	48.5%	43.9%	45.3%	14.3%		71.4%	CWT	2010/11
	15 Two-week wait referrals with suspected breast cancer (Number per 100,000 population)	39	371	264	507	399	378	125		754	CWT	2010/11
	16 Two-week wait referrals with suspected lower GI cancer (Number per 100,000 population)	26	247	161	362	185	282	53		510	CWT	2010/11
	17 Two-week wait referrals with suspected lung cancer (Number per 100,000 population)	8	76	33	150	47	70	0		211	CWT	2010/11
	18 Two-week wait referrals with suspected skin cancer (Number per 100,000 population)	21	200	124	305	238	323	48		1,158	CWT	2010/11
Presentation & diagnostics	19 In-patient or day-case colonoscopy procedures (Number per 100,000 population)	55	523	394	680	450	563	157		723	HES	2010/11
	20 In-patient or day-case sigmoidoscopy procedures (Number per 100,000 population)	17	162	94	259	198	406	0		498	HES	2010/11
	21 In-patient or day-case upper GI endoscopy procedures (Number per 100,000 population)	131	1,245	1,041	1,478	892	1,069	501		1,322	HES	2010/11
	22 Number of emergency admissions with cancer (Number per 100,000 population)	55	523	394	680	434	563	249		703	HES	2010/11
	23 Number of emergency presentations (% of presentations)	9	15.5%	8.4%	26.9%	20.9%	23.8%	4.3%		57.1%	RID	2008
	24 Number of managed referral presentations (% of presentations)	28	48.3%	35.9%	60.8%	49.2%	49.2%	11.1%		69.6%	RID	2008
	25 Number of other presentations (% of presentations)	21	36.2%	25.1%	49.1%	29.9%	27.1%	9.1%		68.7%	RID	2008

Version 2.0, December 2011. We welcome comments and suggestions as to how to make future versions and iterations more relevant and useful for those who will use them. You can email us with your feedback at profiles@ncin.org.uk



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