Improving Outcomes: A Strategy for Cancer

Second Annual Report 2012
### Document Purpose
For information

### Gateway Reference
18385

### Title
Improving Outcomes: A Strategy for Cancer - Second Annual Report

### Author
Department of Health

### Publication Date
11 December 2012

### Target Audience
PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads

### Circulation List
Voluntary Organisations/NDPBs

### Description
Improving Outcomes: A Strategy for Cancer (January 2011) aims to help the reformed NHS deliver cancer outcomes that are amongst the best in the world. This publication reports on progress in 2012

### Cross Ref
Improving Outcomes: A Strategy for Cancer (January 2011)

### Superseded Docs
N/A

### Action Required
N/A

### Timing
N/A

### Contact Details
Mr Tim Elliott
Department of Health, Cancer Policy Team
Area 6B, Skipton House
80 London Road
London SE1 6LH
Tim.Elliott@dh.gsi.gov.uk

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Improving Outcomes: A Strategy for Cancer

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Foreword

Foreword by Professor Sir Mike Richards, National Cancer Director

It is now nearly two years since the Government published Improving Outcomes: a Strategy for Cancer, and I am delighted to have the opportunity to report on progress in implementation.

While the Strategy covers all aspects of the Public Health, NHS and Social Care Outcomes Frameworks, it was in terms of improving survival rates that it set its most challenging ambition. This was to save an additional 5,000 lives per year by 2014-15 – which was roughly in line with halving the gap between the survival rates in England and those in the best countries in Europe.

We do not have the data yet to measure performance against that ambition, but we do have data which shows that there have been improvements in survival rates, and we know that actions are underway to help deliver the ambition. In particular, the age ranges for the breast and bowel screening programmes continue to be extended, campaigns are running to encourage people to go to their doctor if relevant symptoms persist (in order to get the cancer diagnosed when it is more treatable) and patients' access to radiotherapy continues to rise. We are routinely publishing data to demonstrate variations in intervention rates, in order to tackle inappropriately low levels of curative treatment. Mortality rates also continue to improve – not just because of improved survival rates, but also because of lifestyle changes, particularly the reduction in smoking.

The patient experience survey for 2011-12 has demonstrated significant improvements in cancer patients' experience of care, since 2010, across most of the country. This is very encouraging.

In terms of Domain 2 of the NHS Outcomes Framework (improving quality of life), it is difficult to assess whether there have been any improvements in the wellbeing of cancer survivors, because last year was the first in which we collected information about cancer survivors. But now that we have started to collect this data, we have an excellent baseline against which to assess progress.

And there have been other very important developments in terms of the intelligence available to allow proper assessment of the quality of cancer services – in particular,
we are now routinely collecting radiotherapy data and we have begun to collect detailed information about usage of chemotherapy and access to diagnostic imaging.

While there have been these important developments, as ever, much more needs to be done. We need to continue to:

- raise awareness of the scope to prevent cancers, through lifestyle changes, and support people to make the necessary lifestyle changes – many of which will also have more immediate impact on incidence of other diseases, such as diabetes and cardiovascular disease

- work to improve cancer survival rates, particularly through completing the age extension of the breast and bowel screening programmes, introducing flexible sigmoidoscopy bowel screening, tackling late diagnosis of symptomatic cancers and ensuring that all patients who can benefit have access to the best possible curative treatments

- improve the quality of life of cancer survivors, acting on the information from the PROMs survey to develop the services they need and on the increasing evidence base about what works in supporting them to live as healthy a life as possible for as long as possible

- improve patient experience through taking action on the issues identified as needing tackling in the latest results from the cancer patient experience survey.

In the year ahead, while recognising the challenges associated with transition to the new NHS, we need to build on what is good from the past, and take the opportunities presented by the new architecture. There are risks associated with transition, but we must all act to ensure that they do not detract from our focus on improving cancer outcomes.

Professor Sir Mike Richards
National Cancer Director
1. The power of information

Introduction

1.1. *Improving Outcomes: a Strategy for Cancer* \(^1\) (IOSC, January 2011) and the first report on implementing the Strategy \(^2\) (December 2011) set out the importance of information as a key driver in improving outcomes for cancer patients. This chapter reports on improvements in the collection of data and data analyses – and what they tell us - during this past year and highlights priorities for future work.

1.2. The Government has set a clear strategy for the use of information to improve health outcomes. On 21 May 2012, the Department of Health published *The power of information: Putting all of us in control of the health and care information we need* \(^3\), which sets out a ten-year framework for transforming information for the NHS, public health and social care. The focus of that strategy is on improving access to information, providing a framework and a route map to lead a transformation in the way information is collected and used. Information and transparency can drive up standards, leading to safer, more integrated care and more effective prevention of ill health. The work we are doing on promoting the use of information about cancer services and outcomes is very much in line with – and builds on – that strategy.

1.3. In December 2011, to coincide with the first annual report on IOSC, we published *An Intelligence Framework for Cancer* \(^4\). This highlighted our areas of strength and those of weakness, and included details of steps to be taken to improve in key areas, progress against which is reported in this chapter.

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Collecting better information

**Cancer Outcomes and Services Dataset (COSD)**

1.4. If data are recorded in different ways, with different definitions, it is difficult to compare like with like, let alone identify true outcomes or inequalities. Having a single overarching clinically defined dataset is therefore an essential step towards being able to produce robust comparable analyses across the country. The Cancer Outcomes and Services Dataset (COSD – ROCR/OR/2142/FT6/001MAND) is the key dataset which is designed to define and deliver consistency in data recording, data submission and analysis across cancer services in the NHS, including diagnostics, staging, treatment and demographic information.

1.5. After several years of work led by the National Cancer Intelligence Network (NCIN) in collaboration with the cancer registries, Cancer Networks and clinical experts, the COSD has now received full stage approval from the NHS Information Standards Board (ISB) and the new COSD Information Standard (ISB1521 Amd64/2010) has been published by the NHS ISB.

1.6. This mandates submission of the dataset for all NHS providers from 1 January 2013. This will finally enable the collection and use of a standardised cancer dataset to support the challenge of improving patient outcomes, and providing cancer services which are amongst the best in the world. Its principles include the use of existing NHS data flows where appropriate, collecting information once only and defining data items based on clinical practice wherever possible. The new National Cancer Registration Service (NCRS) will bring this information together from multiple routes to compile the complete dataset.

1.7. There will be a phased approach to implementation and only the generic core dataset plus any site specific stage items will need to be submitted initially. An implementation guide outlining initial steps for providers and Networks is available on the NCIN website.

**Chemotherapy – Systemic Anti-Cancer Therapy (SACT) dataset**

1.8. After an extensive period of testing to comply with NHS Information Standards, the chemotherapy dataset (SACT – ROCR/OR/2110/001MAND) went live across the NHS as planned in April 2012, with a two-year

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implementation plan through to the end of March 2014. The dataset covers the collection of treatment data on all adult solid tumours, haematology and paediatric chemotherapy programmes. We will shortly have far greater understanding of all chemotherapy regimens prescribed for cancer. And we will be able to link that information with other relevant data on services and outcomes.

1.9. The Oxford Cancer Intelligence Unit collates monthly activity data and provides regular updates on implementation and chemotherapy activity by provider.

1.10. The data has shown variation in regimen names with several thousand local regimen names in use by clinical teams. This number will increase substantially as more Trusts submit data. Some of the regimens submitted match the Office for Population Censuses and Surveys (OPCS) Classification of Surgical Operations and Procedures Regimen List but a large proportion does not. To enable useful analysis of the data the Intelligence Unit has developed a regimen mapping process which requires constant updating as clinical practice and OPCS commissioning groups change.

1.11. From January 2013 the plan is to make extract files available to the NCRS by the 30th working day after month end, plugging a key data-gap which was identified in the Public Accounts Committee report. The extract files will be produced by the NCIN Chemotherapy Unit, and will be summary analytical extracts of the raw data which is submitted from the Trusts.

Radiotherapy

1.12. The Radiotherapy Dataset (RTDS) now holds three years’ data. On 6 November 2012, we published Radiotherapy services in England 2012. This report has used the three years data collection to provide a clear picture of the state of radiotherapy services around the country and to use the data to review the metrics for radiotherapy set out in the National Radiotherapy Advisory Group (NRAG) report of 2007, resetting them where appropriate.

1.13. In 2010-11, the RTDS showed activity at 33,000 attendances per million population (pmp), compared with 31,000 for the previous year.

1.14. The modelling tool Malthus, launched at the end of 2011, has examined best practice in radiotherapy prescribing and combined it with detailed local

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

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population data. It shows the requirement for 2010 as 48,000 attendances pmp across the country as a whole. This suggests that a 45% increase in attendances is now required to close the gap in provision. However, the capacity will need to increase to 55,000 by 2016 to meet rising demand, a 67% increase on current activity.

1.15. Analysis of the RTDS collection appears to show significant variation in uptake of, and access to, radical radiotherapy that is age dependent with fall off beyond the age of 69 years. Further analysis of the data is required to examine how much of this is clinically understandable, because of stage of disease and co-morbidities, and how much is not.

1.16. The dataset has also identified unacceptable variation in radiotherapy dose-fractionation in some disease sites. Data are now available through the Cancer Commissioning Toolkit (CCT) so that services can assess against benchmark data and commissioners can model radiotherapy demand more accurately and work with providers to minimise unacceptable variation in dose fractionation by ensuring that practice in local teams is evidence based.

1.17. The radiotherapy data have begun to flow into cancer registries and are now being used in the process of cancer registration. In December 2012, a comprehensive analytical summary was produced to link the national Cancer Data Repository, allowing the NCIN to begin national analyses of major treatment interventions.

1.18. The National Audit Office report in 2010\(^8\) concluded that some radiotherapy machines were underutilised with wide variations in throughput. Currently, average attendance per machine is 7,333 attendances, which is in line with the NRAG recommendation.

1.19. Providers and commissioners are now also able to use data available on the CCT to benchmark unit cost activity and make full assessments of the productivity of services to assist in early planning. This will help them to understand variations in costs and the impact of the planned introduction of tariff for 2013-14.

1.20. The NRAG report recommended that 306 linear accelerators (linacs) would be needed by 2011 to meet the anticipated demand. The number of machines has increased since the report with the RTDS showing that 265 were in clinical use in 2011-12. With a throughput indicator of an average of

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\(^8\) *Delivering the Cancer Reform Strategy*, Report by the Comptroller and Auditor General, National Audit Office, HC568, Session 2010-11, November 2010

7,300 attendances per machine (working a standard day), to meet the current gap in activity, it is estimated that 345 machines are required. Of the 265 machines currently in use, 26 are now past their recommended replacement age and a further 59 will require replacement within the next 3 years.

1.21. *Radiotherapy services in England 2012* also sets out the position in terms of use of intensity modulated radiotherapy, which is discussed in Chapter 4.

**Diagnostic imaging**

1.22. The Diagnostic Imaging Dataset (DID) went live on 14 May 2012 to provide information about diagnostic imaging tests for NHS patients across the country. Data have been collected on imaging tests taking place from April 2012 onwards. These data will 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.

1.23. The collection involves providers of NHS-funded diagnostic imaging services extracting data from local Radiology Information Systems and uploading them to a central system, which is managed by the Health and Social Care Information Centre (HSCIC). 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.

1.24. The first data from the DID was published on 22 November 2012. Annex A sets out some summary analyses which show variations around the country for the three key diagnostic tests (chest x-ray, non-obstetric ultrasound and brain Magnetic Resonance Imaging – MRI), including counts for tests referred via GP direct access and as a percentage.

1.25. In line with other transparency commitments, the HSCIC will make data available to support publication via a number of routes, including web-based statistical publications and new indicators in the NCIN GP practice profiles for cancer. 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. The data within the DID will also be linked to the NCRS to provide missing clinical pathway data for existing cancer cases and help ensure that the information to assess tumour stage is available to the NCRS.
Modernising the cancer registration process

Migration to a single national cancer registration system (ENCORE)

1.26. As we reported last year, all the cancer registries are in the process of migrating to ENCORE. Work has progressed through 2012 with all registries undertaking significant additional transitional work around duplicate resolution, historical coding, mapping to the new COSD, aligning all existing electronic data sources to the new standard format, and obtaining a whole new range of electronic data sources covering new pathway elements such as multi-disciplinary teams (MDTs).

1.27. This migration is arguably the largest one of its kind of any cancer registration system in the world. It is crucial that the full historic dataset is transferred to the new system. This creates difficulties when dealing with over 40 years of separate regional data processing and 12 ICD classification systems. It is not surprising therefore that some delays have been experienced, though the plans are still that all registries will be in a position to deliver the benefits of the new single system by the time the registration function transfers into Public Health England (PHE) from 1 April 2013.

1.28. As part of the transfer of the cancer registries, other disease registries and the NCIN into PHE, PHE is working with the HSCIC to ensure maximum benefit is realised in terms of the storage, linkage, management, quality assurance, interpretation and delivery of information to facilitate the provision of a world class public health intelligence service by PHE.

Staging

1.29. Improving the levels of staging recorded in clinical practice, and the way these data are reported and used, is essential to improve understanding of variation in practice and survival across the country and to drive and demonstrate improvements.

1.30. Improved staging continues to be a substantial piece of work. The National Staging Panel has been developing a series of consistent staging algorithms, which are being taken through the NCIN Site Specific Clinical Reference Groups (SSCRGs) for clinical approval. These will underpin the working of registry staff using the new national system, ENCORE.

1.31. The aim for staging across cancer sites is set at 70% of all cancer cases. This figure represents the aggregate stage completeness across all cancer sites and takes into account those patients who cannot be staged for perfectly legitimate clinical reasons and those tumour sites that are not
staged. Taking all these into account gives a figure of around 70% of all cancers that can be staged.

1.32. As a first step to meet the staging aims, all registries have been working with providers to collect extended datasets to meet the improved staging requirement. Monthly reporting to assess the quality of provider data has been introduced to monitor progress.

1.33. The underlying data required for staging are being collected from multiple electronic sources, so that the provenance and history of each data source can be understood. Sources include hospital administrative datasets, pathology, MDT information systems and imaging. Standard Operating Procedures are being tested by the registry specialists to ensure the staging rules defined by the staging panel can be comprehensively adopted by registry staff.

1.34. The registries have committed to being in a position to collect stage data on 70% of cases by the end of 2012. To achieve this, registries need data of sufficient quality from their providers, with rules in place to which registry staff can operate. Whilst collecting and validating stage data will be constrained by the complexity of the clinical processes involved and the data sources, we expect to have completed 85% of the 70% of the staging on 2012 cancer cases by September 2013.

**Timeliness**

1.35. For the 2010 registrations, all registries completed the registration process by the end of 2011. Registries are currently going through migration to a single national registration system (ENCORE), and implementing wholesale changes in data access, management and processing to improve the consistency and levels of staging. Despite this, projections show that all registries will match the previous year’s performance and complete the 2011 registrations by the end of 2012.

**Analyses to inform and drive change**

**Cancers diagnosed via emergency routes**

1.36. NCIN has undertaken additional work to analyse how the routes to a diagnosis for all cancer patients across a three year period, with results available for 38 cancer sites. In September 2012, the methods and results of
this complex and innovative work were published in a peer reviewed journal\textsuperscript{9}. The summary data tables were put into the public domain as part of the ongoing commitment to information transparency. Annex B shows the proportion of cancers diagnosed through each route by age groups for all cancers combined and breast and kidney cancer. 12-month relative survival is also presented by age group for breast and kidney cancer. This demonstrates variations in percentage by route and in corresponding relative survival estimates.

1.37. Work undertaken by the NCIN in 2012 also led to a new method for estimating the proportion of cancers diagnosed as an emergency using rapidly available data. Stage at diagnosis, age at diagnosis and the presence of co-morbidities are associated with a worse prognosis in the first year after diagnosis. Even adjusting for these factors, emergency presentation is associated with a worse prognosis in the first year after diagnosis, although we do not yet know if emergency presentation is directly causing this worse prognosis or whether it is due to some further clinical process or behavioural factor. Analysis of emergency presentations could be a useful proxy measure which cancer services can use as closer to real time to monitor the effect of public health interventions. The NCIN anticipates that the first set of the new proxy measures will be produced early in 2013.

1.38. Following the successful initial production of a range of cancer profiles, the NCIN and the National Cancer Action Team (NCAT) have extended their content and use. Additionally, and for the first time, the GP practice profiles for cancer have now been put into the public domain as part of the ongoing commitment to information transparency\textsuperscript{10}. Because the data in the profiles are both comprehensive and complex, the NCIN have been working with their partners to present this in different ways for different audiences. We have already seen the use by a range of bodies of data from one of the MDT-based service profiles, including Macmillan Cancer Support, who launched an online information tool for colorectal cancer patients using information taken from the profiles but contextualised by Macmillan staff. Whilst this is positive, exploiting the huge range of data which are now becoming available remains a significant challenge for the NCIN and its partners.

\textsuperscript{9} Elliss-Brooks et al, \textit{Route to diagnosis for cancer – determining the patient journey using multiple routine datasets}, British Journal of Cancer, advance online publication 20 September 2012; doi: 10.1038/bjc.2012.408
http://www.nature.com/bjc/journal/vaop/ncurrent/abs/bjc2012408a.html

\textsuperscript{10} GP Practice Profiles at http://ncin.org.uk/cancer_information_tools/profiles/gp_profiles.aspx
1.39. All profiles provide a range of comparative information, and form an important part of the support pack for commissioners, with the CCT being the main entry point for commissioning information. The NCIN have a planned programme to provide MDT-based service profiles across a whole range of different cancer sites. The breast and colorectal profiles will be updated by the end of 2012, and the first set of profiles for lung cancer services will be released in April 2013.

**International Cancer Benchmarking Partnership (ICBP)**

1.40. The first findings of the ICBP, published in The Lancet in January 2011\(^{11}\), demonstrated that English cancer survival rates lag behind the best performing countries in the partnership and that, with the exception of breast cancer, we are not narrowing the “survival gap”. The improvement needed to halve the gap between England and the best performing countries has been charted by the London School of Hygiene and Tropical Medicine (see Annex C). The results show the scale of the challenge that still faces England.

1.41. Analysis has been undertaken by the ICBP on the impact that stage and treatment have on survival rates for each cancer within the study. The partnership has published a new methodology for comparing different cancer registry stage data for international analysis\(^{12}\), and has completed papers on what role stage at diagnosis has on international differences on cancer survival\(^{13}\). The evidence produced from this work has found that for breast, bowel, lung and ovarian cancers, one year survival for cancer patients was generally lowest for the UK across all the stages, but particularly for late stage. The variation found in survival by stage suggests differences in the quality of and access to stage-specific treatment between countries, and unequal access to optimal treatment, particularly in the UK.

1.42. The ICBP has also published results on the first international comparison of population awareness and beliefs in relation to cancer, helping to identify

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where interventions should be targeted\textsuperscript{14}. This research found that the UK had similar levels of knowledge around symptom awareness and similar levels of belief about cancer outcomes, but lower levels of knowledge around age as a risk factor. Most notably, in comparison with other countries, the UK has a significant barrier in terms of people not wanting to waste the doctor’s time and, to a lesser extent, embarrassment.

1.43. Future priorities for the International Partnership include:

- exploring differences in primary care between countries that might impact on primary investigation and onward referral of patients with possible cancer

- mapping the different levels of access to primary care, diagnostic tests and other parameters within the cancer systems of the ICBP

- developing the first robust international comparison of the time intervals from first symptom(s) until diagnosis and start of treatment for cancer patients in order to test the hypothesis that longer time intervals can contribute to poorer cancer outcomes. This work will also describe and compare the various routes that patients take to enter the cancer pathway and how they are diagnosed in order to identify possible targets for actions to reduce delays.

**National cancer audits**

1.44. There are four ongoing national cancer audits: bowel cancer; head and neck cancer; lung cancer; and oesophago-gastric cancer.

1.45. The migration of cancer registries onto a single processing system (ENCORE) provides a new mechanism to manage national cancer audits, using rapidly available registration data as the core. The first audit to migrate to the ENCORE platform in 2012 was the national Breast Cancer Clinical Outcome Measures (BCCOM) breast audit which transferred during the summer. The Healthcare Quality Improvement Partnership (HQIP), which commissions the majority of national audits, has recently approved a new national audit of prostate cancer, with the winning proposal being a joint tender led by the Royal College of Surgeons with the NCIN, and the ENCORE system as the information delivery platform.

Further work is ongoing on the scope to put the ENCORE system at the heart of all national cancer audits, reducing the burden of data collection, ensuring consistency and blending the data used for registration with that used for audit.

**Metastatic breast cancer collection**

The results from a joint project between Breast Cancer Care, the NCIN and the Association of Breast Surgery to collect data on recurrent and metastatic breast cancer have been encouraging, and the report of the pilot was published in March 2012. But the focus now has to be to ensure that this becomes standard practice for all breast teams around the country.

From April 2012, all teams treating breast cancer patients have been required to submit information on all patients diagnosed with a new recurrence of metastatic disease to their regional registry through the Cancer Waiting Times process. We will shortly be reviewing the first six months of data. These are collected as part of the COSD approvals.

**Equality**

The National Cancer Equality Initiative (NCEI) and the NCIN have worked to identify areas of excellence in the use of information on equality, an example being the tool produced in the North West to evaluate equality metrics by MDT. This innovative approach has been presented to the NCEI and is being provided to all Cancer Networks in the country.

Working with the NCEI, the NCIN has specified and agreed a range of high-level equality metrics which will be undertaken to an agreed regularity (see Annex D). These include metrics on incidence, mortality and survival, but also processing metrics such as the proportions of ethnicity coding recorded by providers. Further metrics cover cancer screening, routes to diagnosis, treatment, patient experience and patient reported outcomes. All the metrics use existing data sources, so no new collections are required.

The NCIN has continued to put equality at the heart of all that it does. Further work has been done on the routes to diagnosis analyses published in September 2012 to provide information on routes by gender, age, deprivation and ethnicity. The new COSD also supports collection and analysis by equality characteristic.

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15 *Recurrent and Metastatic Breast Cancer Data Collection, Pilot Report, March 2012, Association of Breast Survey/Breast Cancer Care/NCIN* 
NCIN analyses published during 2012

1.52. The table at Annex E shows the range of analyses published by the NCIN over the last year.

Information and Research

Collecting NHS numbers to enable future research

1.53. Work in 2011 demonstrated the new knowledge which could be generated on patients recruited to trials and those with similar characteristics who were not. However, such work was hampered by problems with routine data linkages across datasets, with not all trials collections using the NHS number.

1.54. To facilitate future linkage of data, in March 2012 the National Cancer Research Institute introduced the mandatory collection of NHS numbers across their efficacy and population-based trials.

1.55. Such linkages will support easier long-term follow up of patients in trials using routinely collected NHS data which will flow into the new National Cancer Registration Service. In terms of information flowing from ENCORE into the trials domain, the first set of data into a research project is now flowing from the ENCORE system, into the long term follow up of the trial of flexible sigmoidoscopy.

1.56. There continue to be a significant number of publications using data from the NCIN linked to the Clinical Practice Research Datalink (CPRD, formerly GPRD), which allows bona-fide researchers access to linked primary care, cancer registry and hospital activity data.

Making intelligence more accessible and user friendly

1.57. In addition to providing reports, analyses, briefings and targeted outcomes, the NCIN continues to put more and increasingly granular data into the public domain in line with the Government’s transparency agenda. However, simply putting data and information into the public domain does not in itself drive change or inform patients.

1.58. During 2012, NCIN has worked with the bone cancer charity, Sarcoma UK, to provide commentary for a public audience. As mentioned previously, the NCIN also worked with Macmillan Cancer Support to pilot a new public-friendly website for colorectal cancer in June 2012; Macmillan are considering the next steps for this project. Many other cancer charities are also providing data about services and outcomes broken down by
geographical area, helping patients to make informed decisions about their care.

1.59. In October 2012, the National Cancer Peer Review Programme (NCPR) piloted a patient-friendly portal, *My Cancer Treatment*, which used routinely available data presented in a way to be understandable and informative to patients.

1.60. The NCIN is committed to providing information and data in format appropriate to the audiences using them. This work will continue to be taken forward in 2013 in partnership with a number of stakeholders, including the cancer charities.

**Priorities for 2013**

1.61. National cancer registration will undergo the final phases of its comprehensive modernisation programme in 2013. A challenging year lies ahead, including the management of the new COSD from January 2013, the migration and live running of a single national system (ENCORE) and the reorganisation of management and accountability, with the establishment of a single national Deputy Director for Disease Registration within PHE from April 2013. Achieving the aim of collecting high quality staging data on 70% of cancer cases will also be important in 2013.

1.62. Whilst this is underway, we have rising expectations for increasingly focused, timely and relevant information and intelligence delivery, which will require efforts by all NCIN partners – Department of Health, PHE, the NHS and the charitable sector – to ensure the knowledge generated is understood, communicated and acted upon widely.
2. Public Health outcomes

Introduction

2.1. There were around 269,000 new cases of cancer in 2010, a rise of nearly 4,000 on 2009. Cancer Research UK (CRUK) estimate that about a third of cancers are caused by smoking, diet, alcohol and obesity\textsuperscript{16} and has estimated that, by 2030, there will be 432,000 new cases of cancer each year. That is why our work to prevent cancer is so important, along with our work to diagnose cancer earlier.

2.2. This chapter focuses on progress on prevention and early diagnosis of asymptomatic cancer through screening. Public Health services are also very important in the early diagnosis of symptomatic cancer – however, because responsibility here is shared with the NHS, for simplicity we have covered progress on early diagnosis of symptomatic cancer in Chapter 3.

New arrangements for Public Health

2.3. Plans are well developed for certain parts of the national cancer programme to move into Public Health England (PHE) from April 2013. These include: national coordination and quality assurance of cancer screening programmes; elements of the programme to promote early diagnosis of symptomatic cancer; cancer registration; and the National Cancer Intelligence Network (NCIN). PHE will also have responsibility for piloting and roll out of new screening programmes and extensions to existing programmes.

2.4. The NHS Commissioning Board (NHS CB) will commission existing routine cancer screening programmes through an agreement between the Department of Health (DH) and the NHS CB, based on evidence based specifications. The specifications are part of the agreement on public health functions to be exercised by the NHS CB made under Section 7A of the NHS Act 2006, as inserted by the Health and Social Care Act 2012. They cover: the scope of the cancer screening programmes; delivery of the programmes; operational requirements and quality assurance; and teaching and research activities.

\textsuperscript{16} Parkin et al, \textit{The Fraction of Cancer Attributable to Lifestyle and Environmental Factors in the UK in 2010}, Br J Cancer 105, Issue S2 (S1-S81)
2.5. The Public Health Outcomes Framework (PHOF) and the NHS Outcomes Framework\textsuperscript{17} (NHS OF) provide the indicators that will incentivise joint working against which progress will be reported. The indicator “under 75 mortality rate from cancer” is shared between the PHOF and the NHS OF, recognising the critical contribution that the NHS can make to reducing “mortality amenable to healthcare” and the contribution the public health services can make to reducing “preventable mortality” through their role in supporting earlier diagnosis and encouraging people to make healthy lifestyle choices.

2.6. In having a shared indicator, with joint accountability for delivery, PHE and the NHS CB will have the incentive to work together on appropriate activity to achieve earlier diagnosis and these indicators will enable us to assess progress in improving cancer mortality.

2.7. The PHOF has a range of other indicators relevant to cancer including: cancer screening coverage; the proportion of cancers diagnosed at stages 1 and 2; rates of smoking prevalence; and human papillomavirus (HPV) vaccination uptake.

2.8. Updated policy documents\textsuperscript{18} to reflect technical developments since the PHOF was first published in January 2012 were issued on 20 November 2012, along with the first set of baseline data\textsuperscript{19} for 39 of the 66 indicators (via an interactive web tool - www.phoutcomes.info).

2.9. Clearly, effective partnership working locally is critical to promoting cancer prevention and earlier diagnosis. Through health and wellbeing boards, clinical commissioning groups (CCGs) and local authorities will be required to undertake an assessment of the current and future health and social care needs of the local population through Joint Strategic Needs Assessments (JSNAs). Based on this they will develop Joint Health and Wellbeing Strategies (JHWSs) to address the identified needs, and these will underpin commissioning plans for local health and social care services through CCGs, the NHS CB and local authorities.

\textsuperscript{18} http://www.dh.gov.uk/health/2012/11/phof-technical-refresh/
\textsuperscript{19} http://transparency.dh.gov.uk/2012/11/20/phof-data-autumn-2012/
Incidence trends

2.10. The 269,000 new cases of cancer registered in England in 2010 (136,000 in males and 132,000 in females) equate to an age-standardised rate of around 423 and 370 per 100,000 population respectively. The number of registrations has increased by around 1,700 new cases for males and 2,300 for females when compared with 2009. The four cancer types of breast, lung, colorectal and prostate account for over half of the cancer burden in England.

2.11. Between 1980-82 and 2008-10, the age-standardised incidence rate in England for all cancers combined increased by 15% in males and 31% in females. In recent years, the increase in cancer rates has been less marked than in earlier years, in particular for females. Between 2001-03 and 2008-10, the age-standardised incidence rates in England increased by 4% in males and 6% in females.

2.12. 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 2001-03 and 2008-10 age-standardised cancer incidence rates in those aged 75+ were relatively stable in males, and increased by 6% in females. Over the same period, age-standardised incidence rates increased for people aged 65 to 74 by 9% in males and 12% in females, whilst for people aged under 65 the increase was 11% in males and 8% in females.

2.13. The 2011 CRUK study referred to earlier 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

2.14. 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 OF, but here we cover changes in mortality, as cancer mortality changes are an indicator within the PHOF as well as within the NHS OF.

2.15. The latest data for 2008-10 show an improvement in the cancer mortality rate (ages under 75) for England, continuing the previous trend (see Figure 2.1). 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).
Figure 2.1 Cancer Mortality in England (ages under 75)
Three year average death rates from cancer in England 1999-01 to 2008-10 for persons under 75

![Graph showing cancer mortality rates from 1999-01 to 2008-10](image)

- Change since 1999-01: A fall of 14.5%

Prevention

HPV Vaccination Programme

2.16. Published preliminary uptake data for HPV vaccinations given in the academic year 2011-12 up to June 2012 show that uptake in the routine cohort of 12-13 year-old girls for first (90.4%), second (89.0%) and third (82.6%) doses exceeds that for the same month in all the previous academic years since the vaccination programme began. These are some of the highest HPV vaccine uptake figures in the world. HPV vaccination has been included in the PHOF population vaccine coverage indicator.

SunSmart

2.17. SunSmart is the UK's national skin cancer prevention campaign, and DH has funded CRUK, under the SunSmart banner, to continue to lead much of the skin cancer prevention campaign activity. In 2012-13 DH has built on the successes of previous years by continuing to target young people aged 16-24 with the key messages of the importance of avoiding sunburn and the dangers of sunbed use (especially by those under 18). Core activities have
2.18. In summer 2012, CRUK ran a social media campaign to promote SunSmart messages. The *Made in the Shade* campaign aimed to reduce sunburn by encouraging young people to protect themselves from the sun. Throughout the summer, the campaign put the spotlight on the shade and positioned it as an interesting and inspirational place to spend time. DH supported this work by funding additional specific events that expanded the reach of the campaign at three festivals: HardRock, Wireless, and Bestival.

2.19. DH also commissioned and launched a separate campaign, *Flag It*, to encourage young people to look out for each other whilst enjoying the sun. The campaign highlighted the dangers of UV exposure and skin cancer by asking sun seekers to “flag it” when a friend needs to cover up, apply some sunscreen or stay in the shade. The *Flag It* PR activity launched in July and coverage included the Sky News Radio network, (covering more than 280 stations with a weekly audience of nearly 34 million), 2 pieces of national online coverage, 24 pieces of consumer coverage, 12 pieces of regional coverage including two front covers and achieved a total Twitter reach of 885,179.

2.20. CRUK has produced an educational campaign to help GPs identify red-flag skin cancer symptoms. This includes a GP Skin Cancer Toolkit which was launched on 29 June and is being promoted via doctors.net as part of an education campaign, ensuring that the toolkit is in the minds of GPs. The launch followed a pilot in the South West and North West of England. Plans are underway to evaluate the impact of the toolkit and will assess any increases in GP knowledge, the appropriateness of referrals into secondary care, as well as assessing pre/post referral accuracy into dermatology services over a calendar year.

2.21. DH has funded a targeted direct mail campaign in Greater Manchester aimed at 10,000 men over 50 and 10,000 women as influencers of men over 50 to see which has the most positive effect on patient presentations with skin cancer concerns.

### Smoking

2.22. Tobacco use remains one of our most significant public health challenges. Smoking is the biggest preventable cause of death in England causing almost 80,000 premature deaths each year, and is one of the most significant...
causes of health inequalities. In 2011, almost three in ten of all deaths from cancers in this population are estimated to be caused by smoking.

2.23. DH published its *Tobacco Control Plan* in March 2011. The plan 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 five years post-plan to drive down the prevalence of smoking and to support comprehensive tobacco control in local areas.

2.24. Key commitments in the *Tobacco Control Plan*\(^{20}\) that have already been delivered include:

- prohibiting sales of tobacco from vending machines since 1 October 2011
- publishing a consultation on standardised packaging of tobacco which was open from 16 April to 10 August 2012
- running a marketing campaign to highlight the risks to health of secondhand smoke in the home and family cars (with the success of smokefree laws, the home and family car are now the most likely places where people will be exposed)
- implementing legislation to end tobacco displays in large shops and supermarkets from 6 April 2012
- publishing a three-year marketing strategy for tobacco control in September 2012\(^{21}\).

2.25. The *Tobacco Control Plan* also includes future commitments to:

- implement legislation to end tobacco displays in small shops by 6 April 2015
- analyse the responses to the plain packaging consultation to consider if introducing standardised 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


\(^{21}\) *Smokefree Marketing Campaign Strategy*, NHS/SMOKEFREE, September 2012-12-03
• 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 taxation 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.

2.26. Through the comprehensive action described in the plan, we want to reduce 
smoking rates faster in the five years post-plan than in the five years prior to 
publication of the plan. 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).

Obesity

2.27. The Government set out its commitment to tackling overweight and obesity 
across the life course in A Call to Action on Obesity in England22, published 
in October 2011. The document set out the action that Government will take 
and calls on a wide range of partners to play their part. As part of the 
approach, key national programmes such as the Change4Life social 
marketing strategy and the National Child Measurement Programme are 
continuing. The Public Health Responsibility Deal is helping people to cut 
their calorie consumption - some 9,000 food outlets will include calorie 
labelling by the end of the year, and more than 20 major companies have 
signed up to the calorie reduction pledge. Steps are also being taken to 
encourage people to be more active - the Games4Life campaign saw 
294,854 people receive a personalised activity plan, and Change4Life sports

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22 Healthy lives, healthy people: a call to action on obesity in England (Department of Health, October 
2011) 
clubs, which are targeted at the least active children, have engaged over 150,000 children and young people in sport and physical activity.

2.28. Local authorities will also have a key part to play in this, and from 1 April 2013, will assume the leadership role for promoting health locally, including encouraging the integration of commissioning of health, social and public health services for its population. To do this successfully local authorities will be supported by PHE, through the provision of evidence, advice and tools needed to drive improvements in health.

**Alcohol**

2.29. The Government wants to turn the tide against irresponsible drinking and *The Government’s Alcohol Strategy*\(^\text{23}\) (March 2012) sets out how local and central government, the alcohol industry and people themselves can achieve this. The Strategy includes a strong package of health measures, building on the Public Health reforms, including a ring-fenced public health grant to local authorities.

2.30. The Strategy encourages local authorities to work together with Clinical Commissioning Groups to:

- invest further in brief advice (extending activity such as that in the Health Check)
- ensure Alcohol Liaison Nurses are working across NHS hospitals
- provide effective alcohol treatment and recovery.

2.31. There will be an alcohol check within the NHS Health Check for adults from April 2013.

2.32. Dame Sally Davies, the Chief Medical Officer, is overseeing a UK-wide review of the alcohol guidelines so that people at all stages of the life can make informed choices about their drinking.

2.33. The Change4Life campaign helps people check if they are drinking above the lower-risk guidelines or not and offers tips and tools to cut down.

2.34. The Strategy announced steps to stop the sale of very cheap alcohol by introducing a minimum unit price for alcohol and consulting on a ban on multi-buy price promotions in shops. The Government consultation on these

measures was launched on 28 November 2012, with a view to introducing primary legislation in 2013.

**Occupational cancer**

2.35. Currently, occupational ill-health accounts for over 20 million working days lost and an estimated 12,000 deaths per year\(^{24}\). The major ill-health component is occupational cancer, accounting for approximately 8,000 deaths and 14,000 cancer registrations annually. The Health and Safety Executive (HSE) is committed to reducing these numbers, and has a range of activities in place, including interventions with industry stakeholders, targeted inspection initiatives and awareness raising initiatives.

2.36. The intervention mix differs for each priority agent/occupation, with well understood interventions drawing on a sustained programme of activity spanning many years (e.g. asbestos and respirable crystalline silica). For other priorities, the HSE’s work focuses on developing understanding of current exposures and working with and through other stakeholders (e.g. shift work and diesel engine exhaust emissions). The HSE Board has acknowledged that occupational cancer is a serious issue and plan to host a conference/workshop to engage stakeholders in the health and safety community not currently involved in intervention activity to discuss the role they can play and the best ways to share knowledge.

2.37. A study in October 2012 from researchers from the University of Quebec showed that working night shifts raises the risk of men developing prostate cancer by almost three times compared to men working only day shifts\(^{25}\). Men who work night shifts were also at greater risk of bowel, bladder and lung cancer. Most previous studies linking night work to cancer concerned women and breast cancer, particularly nurses.

**Aspirin**

2.38. An international consensus statement on the prophylactic use of aspirin in the general population is due to be published shortly. The statement is likely to say that accumulating evidence supports an effect of aspirin in reducing overall cancer incidence and mortality in the general population, and these benefits are larger and most clearly established for some gastrointestinal cancers.

\(^{24}\) Occupational cancer, priorities for future intervention – supplementary paper - Health and Safety Executive Board, August 2012

2.39. In 2013 we will consider what the international consensus statement means for policy in England, 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. We understand that CRUK is designing future research studies for the use of aspirin in both the primary and secondary care settings.

Cancer screening

Breast cancer screening

2.40. The independent review of the benefits and harms of population based breast cancer screening, led by Sir Michael Marmot, reported in October 2012\(^{26}\), along with a summary in The Lancet\(^{27}\). The review report said that 1,300 lives are saved through breast screening every year in the UK. For every 10,000 women invited for screening, 681 cancers will be diagnosed and 43 deaths prevented. However, of the 681 cases diagnosed, 136 will be overdiagnosed. The review panel concluded that the UK breast screening programmes confer significant benefit and should continue.

2.41. The key now is how we communicate this new information to women so they can make an informed choice for themselves. NHS Cancer Screening Programmes have commissioned independent academics at King’s College London to develop new materials. These new materials will be available in 2013. A “citizens’ jury” of 25 women was held in November 2012 to provide advice on the drafting of a new leaflet. A majority of the women preferred the terms “overtreatment” to “overdiagnosis” and “lives saved” to “deaths avoided”. However, the women did not reach consensus on which matters most in the leaflet, to reassure or to be accurate. The majority wanted the leaflet to do both\(^{28}\).

2.42. The Marmot Review also recommended that the cost-effectiveness of breast screening should be reviewed, and we are considering how best to take this recommendation forward.

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http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61611-0/abstract

\(^{28}\) Nigel Hawkes, “Citizens’ jury” disagrees over whether screening leaflet should put reassurance before accuracy, BMJ 2012;345:e8047
2.43. As at October 2012, 55 out of 80 local programmes (69%) had entered the breast screening age extension randomisation trial, and a further 9 (11%) which are unsuitable for randomisation were inviting only the 47-49 year-olds. Over a million women have been involved in the randomisation trial so far.

2.44. 16 local programmes (20%) are still to expand, citing lack of digital mammography (DM) equipment, staffing shortfalls and funding as issues. As at October 2012, 76 (95%) of local programmes had at least one direct DM x-ray set and 60 (75%) were fully digital. Four programmes (5%) still have no digital machines. Local units with no DM equipment and those only partially converted are shown in Table 2.1. Through Strategic Health Authorities (SHAs) the Department has asked that outlying local units ensure they install the required equipment.

Table 2.1 Local breast screening units with no digital mammography equipment and local units partially converted to digital mammography

<table>
<thead>
<tr>
<th>Local units with no digital mammography equipment</th>
<th>Local units partially converted to digital mammography</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barking, Havering and Brentwood</td>
<td>Central and East London</td>
</tr>
<tr>
<td>North Cumbria</td>
<td>South East London and Queen Mary’s</td>
</tr>
<tr>
<td>Southampton and Salisbury</td>
<td>Nottingham</td>
</tr>
<tr>
<td>Worthing</td>
<td>Leeds Wakefield</td>
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<tr>
<td></td>
<td>Humberside</td>
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<tr>
<td></td>
<td>Pennine</td>
</tr>
<tr>
<td></td>
<td>Norfolk and Norwich</td>
</tr>
<tr>
<td></td>
<td>South Essex</td>
</tr>
<tr>
<td></td>
<td>Portsmouth</td>
</tr>
<tr>
<td></td>
<td>Aylesbury and Wycombe</td>
</tr>
</tbody>
</table>
Local units with no digital mammography equipment | Local units partially converted to digital mammography
---|---
North and Mid-Hampshire
Liverpool
East Cheshire and Stockport
Hereford and Worcester
Lincolnshire

**Cervical screening**

2.45. As at October 2012, 40 local screening services had implemented HPV triage and 80 out of 87 (92%) laboratories processing cervical screening samples had been approved for HPV triage and test of cure. Seven laboratories (8%) remain unapproved, but six of these are expected to be approved in early 2013. Implementation of HPV test of cure will follow. The original six HPV triage sentinel sites will begin piloting HPV Testing as Primary Screening (HPV TaPS) shortly. These sites are: Liverpool; Manchester; Northwick Park, London; Bristol; Sheffield; and Norwich. Women will be screened using a HPV test first, with only those with a positive result going on to have cytology. HPV TaPS will make the programme even more personalised for women, with major cost savings likely. A formal evaluation will determine whether we go ahead with national roll-out. As at November 2012, 99% of women are receiving the results of their cervical screening tests within two weeks.

**Bowel cancer screening**

2.46. Since the NHS Bowel Cancer Screening Programme began in 2006, over 16 million Faecal Occult Blood testing kits have been sent out and over nine million completed and returned by men and women, an uptake rate of 55%. Over 14,000 cancers had been detected, with over 40,000 high risk and intermediate risk polyps identified.

2.47. As at the end of November 2012, 41 out of 58 local screening centres (72%) had extended their programmes to men and women up to their 75th birthday.
Issues around endoscopy capacity in some parts of the country have meant some programmes were not able to implement the age extension on time. Work to improve endoscopy capacity and productivity is addressed in the next chapter. The 17 programmes yet to extend and the dates they were meant to implement the extension by are shown Table 2.2.

Table 2.2 Local bowel screening programmes yet to age extend and the dates they were meant to implement the extension by

<table>
<thead>
<tr>
<th>Local screening centre</th>
<th>Date centre was supposed to implement age extension</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East London</td>
<td>1 April 2010</td>
</tr>
<tr>
<td>Cheshire</td>
<td>1 April 2010</td>
</tr>
<tr>
<td>South East London</td>
<td>1 April 2010</td>
</tr>
<tr>
<td>Nottinghamshire</td>
<td>1 April 2010</td>
</tr>
<tr>
<td>North Staffordshire</td>
<td>1 September 2010</td>
</tr>
<tr>
<td>Sussex</td>
<td>18 November 2010</td>
</tr>
<tr>
<td>Bristol and Weston</td>
<td>2 December 2010</td>
</tr>
<tr>
<td>Bath, Swindon and Wiltshire</td>
<td>17 February 2011</td>
</tr>
<tr>
<td>East Kent</td>
<td>7 April 2011</td>
</tr>
<tr>
<td>North and East Devon</td>
<td>5 June 2011</td>
</tr>
<tr>
<td>Harrogate, Leeds and York</td>
<td>15 June 2011</td>
</tr>
<tr>
<td>Peterborough and Hinchingbrooke</td>
<td>3 July 2011</td>
</tr>
<tr>
<td>Buckinghamshire and Milton Keynes</td>
<td>6 October 2011</td>
</tr>
<tr>
<td>Cornwall</td>
<td>13 October 2011</td>
</tr>
<tr>
<td>Local screening centre</td>
<td>Date centre was supposed to implement age extension</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Shropshire</td>
<td>20 October 2011</td>
</tr>
<tr>
<td>Lincolnshire</td>
<td>30 December 2011</td>
</tr>
<tr>
<td>Oxfordshire</td>
<td>25 January 2012</td>
</tr>
</tbody>
</table>

2.48. DH has estimated that delays in implementing the age extension are costing between 150 and 250 lives a year, and so has asked, through SHAs, that NHS Trusts with local bowel screening centres ensure there is extra capacity to extend their programmes up to age 75.

2.49. The IT system to support flexible sigmoidoscopy (FS) screening is due to be delivered in March 2013, when we expect the pilot sites to begin inviting men and women aged 55 for this additional test which is estimated to save 3,000 lives a year. The pilot sites are: Norwich; South of Tyne; St Mark’s, London; Surrey; West Kent; and Wolverhampton. Up to 20 further sites are preparing to implement FS as part of Wave One of roll-out from October 2013. The plan remains to meet the *Improving Outcomes: A Strategy for Cancer* (IOSC) commitments of 30% roll-out across England by March 2014 and 60% roll-out by March 2015. PHE will be responsible for the piloting and roll-out of FS.

**Priorities for the coming year**

2.50. The Government is currently considering what actions are needed to bring England’s mortality rates in line with the best in Europe. To make the appropriate Public Health contribution on cancer mortality rates, next year we will need:

- to continue the focus on prevention
- to ensure we deliver full age extension of the current bowel cancer screening programme and full participation of screening units, where possible, in the breast screening randomisation project
- all breast screening units to have at least one digital mammography machine, and be moving towards being fully digital
- to keep on track with the introduction of FS screening
• to continue the drive for earlier diagnosis of symptomatic cancer as set out in the next chapter, with PHE and the NHS working closely together to deliver this.

2.51. In addition, we need to ensure that new informed choice information materials for the public will be made available across the cancer screening programmes.
3. NHS Outcomes Framework
Domain 1: preventing people from dying prematurely

Introduction

3.1. The purpose of the NHS Outcomes Framework (NHS OF) 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 (NHS CB) to account for the health outcomes it is securing for patients. The NHS OF is structured around five domains, with each including 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. On 13 November 2012, the Mandate29 and the NHS OF 2013/1430 were published. This confirmed the priorities for the NHS for the next two years, including the need to demonstrate progress against the five domains of the OF, and all of the indicators in the OF – including, where possible, comparing our services and outcomes with the best in the world.

3.4. This and the next four chapters are structured using the five domains as headings, to demonstrate how the work that is being done to implement

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29 The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015 (November 2012)
Improving outcomes: a strategy for cancer (IOSC) supports improvements in these overarching outcomes.

Improving cancer survival rates

3.5. IOSC set out a commitment to deliver improved cancer survival rates. In line with Domain 1 of the NHS OF, it set an ambition to save an additional 5,000 lives per year by 2014-15 – which is designed to halve the gap between England’s survival rates and the best in Europe.

3.6. The Strategy set out how cancer survival rates could be improved by earlier diagnosis of symptomatic cancers and ensuring that everyone who could benefit had timely access to the appropriate high quality treatment. This chapter looks at progress in these areas.

Indicator development

3.7. Since publication of the first NHS OF, work on developing indicators has continued. The Framework for 2013-14 includes a new indicator to measure cancer survival for children. Indicator 1.6iii Five-year survival from all cancers in children will measure cancer survival rates for children and young people under 15 years. The existing cancer survival indicators do not cover children and, as cancer represents a significant proportion of childhood deaths, it is clearly important to extend coverage to this important group.

3.8. Another significant change is the development of new indicators in relation to adult cancer survival. Composite indicators are being developed covering one and five year survival for all cancers combined (1.4.i and 1.4.ii) and for the three cancers accounting for the highest number of deaths (breast, bowel and lung - 1.4.iii 1.4.iv). The inclusion of these indicators was in response to concerns from the All-Party Parliamentary Group for Cancer that the existing survival measures did not capture rarer forms of cancer, as well as the need to ensure national level indicators that would be compatible with potential Clinical Commissioning Group (CCG) level indicators. The Department of Health (DH) therefore asked the London School of Hygiene and Tropical Medicine (LSHTM) to develop these composite indicators at both national and CCG levels. Ensuring that the indicators will be effective and statistically valid at national and CCG level will help to ensure a shared accountability for improvement across jurisdictions. The LSHTM will also calculate values for indicators over time so we have a baseline against which to assess changes.

3.9. The Office for National Statistics (ONS) will continue to publish national site specific data which will enable progress to be tracked for specific cancers.
3.10. It is of course too early to assess improvements in survival rates since we set out the ambition to save an additional 5,000 lives per year by 2014-15. What we can assess is how far we appear to be making general progress in improving survival rates.

3.11. As shown in Figure 3.1, overall the one-year cancer survival index for England has increased during the period 1996–2009, from 59.5% for patients diagnosed in 1996 to 66.5% in 2009.

Figure 3.1 One-year survival index (percent) for all cancers combined: smoothed maps, England, 1996 and 2009, Primary Care Trust

3.12. The most recent ONS data showed that the general trend of increasing five-year net survival continued for patients diagnosed during 2006–2010, with survival improving for all of the 21 most common cancers. However, the International Cancer Benchmarking Partnership (ICBP) has demonstrated that, whilst survival rates have increased generally, they generally remain higher in Australia, Canada, and Sweden, intermediate in Norway, and lower in Denmark and the UK (see Annex D). The patterns are consistent with later stage at diagnosis or differences in treatment, particularly in Denmark and the UK, and in older patients.

3.13. The table at Annex F sets out one- and five-year survival rates by PCT for breast, bowel and lung cancer. While there are issues of statistical significance looking at the PCT data for individual cancers, hence the inclusion of confidence intervals, what can be seen is that there are very
variable survival rates across the country. There is a range of reasons for this, but survival rates in almost all PCTs in England in 2010 are below the average achieved in Australia, Sweden and Canada (“AUSWECAN”) in 2005-7. Tackling variation will help deliver the improvements we need to deliver survival rates in line with the best in Europe.

Improving earlier diagnosis of cancer

Raising public awareness of cancer symptoms and encouraging earlier presentation to primary care

Be Clear on Cancer campaigns in 2012

3.14. DH has continued to run the Be Clear on Cancer national symptom awareness campaigns and to pilot campaigns at a regional and local level. This year, the aim has also been to assess the impact of running campaigns over a longer period and different combinations of activity (eg media advertising and community engagement), and to test new campaigns. Funding has been made available to Cancer Networks to host or run campaigns, as well as to enable them to work with local providers in managing the extra demand that arises from these campaigns. Cancer Research UK (CRUK) is providing programme management, evaluation and social marketing support.

3.15. The 2012 campaigns have included:

- local pilot campaigns for bladder and kidney cancers (“blood in pee”), breast cancer in women over 70 and oesophago-gastric cancer during January to July 2012
- a national bowel cancer campaign which ran from January to March 2012
- a national lung cancer campaign which ran from May to June 2012
- 5-week repeat of the national campaign on bowel cancer at the end of August 2012
- extending the “top-up” bowel cancer campaign in regions of the country over 5-6 months over the period of September 2012 to mid-March 2013.

In addition, the 2012-13 campaigns will include:

- regional pilot campaigns for kidney and bladder cancers (“blood in
pee") and breast cancer in women over 70 from January to mid-March 2013

- a new pilot campaign for ovarian cancer and a new symptoms campaign to raise awareness of the key symptoms common to many cancers, including rarer cancers. These will also run from January to mid-March 2013.

Evaluation of cancer awareness campaigns in 2012

3.16. The campaigns are subject to comprehensive evaluation, with data collected on metrics reflecting key points along the early diagnosis pathway. This includes symptom awareness, attendances to primary care, urgent referrals and diagnostic investigation activity. Cancers diagnosed and staging are also important metrics, but data for these metrics take longer to come through, due to their nature.

3.17. The first national bowel cancer awareness campaign ran from January to March 2012 and contributed to:

- a significant increase in recall of key symptoms of bowel cancer - unprompted awareness of blood in stools (27% to 47%) and loose bowel motions (10% to 23%)

- a 29.3% increase in attendances to general practice (a measure of behaviour change) amongst patients over 50 with the campaign related symptoms. The number of attendances by men reporting campaign-related symptoms during the campaign period increased by 37.2%, compared with 21.9% for women. In terms of age profile, women visiting for directly linked symptoms had an older age profile than did men

- an increase of 40% in two week wait referrals for suspected lower gastro-intestinal cancer between February and April 2012 compared with the same period in 2011, with the increase maintained at 40% in May to June 2012. The large majority (85%) of the referrals were in the over 50 age range

- a drop in conversion rate (referrals subsequently diagnosed with cancer) for the period February to April 2012 compared to the same period in 2011 (5.9% to 4.7%), but a small increase in the detection rate (proportion of cancers diagnosed through the two week wait pathway) for March to May 2012, from 36% to 38%
a significant increase in activity for both colonoscopy and flexible-sigmoidoscopy coinciding with the timing of the campaign, and while there was no overall impact at a national level on long waits, some providers have reported challenges in managing local demand for endoscopy services.

3.18. Initial results of the national lung cancer awareness campaign which ran in May and June 2012 show:

- statistically significant increases in unprompted awareness of cough/hoarseness (41% to 50%) and persistent/prolonged cough (12% to 15%) amongst the target audience
- an increase of approximately 30% in two week wait referrals for suspected lung cancer in the campaign months, compared with the same period in the previous year, with the bulk of additional referrals in the over 50s.

3.19. Data on cancers diagnosed and staging following the national lung campaign will be analysed when available but analysis of national lung cancer audit data following the regional lung cancer awareness campaign piloted in the Midlands region at the end of 2011 has shown some encouraging results. Trusts within the campaign area saw a 14.0% increase in lung cancer cases (excluding mesothelioma) diagnosed for the period October to December 2011 compared with the same period in the previous year, whereas there was only a 4.7% increase in Trusts outside the pilot area. Furthermore, for Trusts inside the campaign region, encouraging staging data were seen with significantly more small cell lung cancers (SCLC) staged as “limited” and a trend towards earlier stage at diagnosis of non-small cell lung cancer (NSCLC). Neither of these results was seen in the non-campaign Trusts. Campaign area Trusts also saw a statistically significant increase in surgical resections which was not replicated in the non-campaign area Trusts, and a trend towards lower performance status at diagnosis.

3.20. From early January 2012, there were also 17 local pilot campaigns focussing on breast cancer in women over 70, bladder and kidney cancer (focusing on the symptom of blood in urine) and oesophago-gastric cancer. Early results from the pilots for breast cancer in women over 70 and blood in urine have been encouraging and these will run as regional pilots in early January 2013.

3.21. Final evaluation reports for all these campaigns are expected in 2013.
Modelling the cost-effectiveness of early awareness interventions for the early diagnosis of lung and bowel cancers

3.22. Building the evidence base for the effectiveness of early diagnosis remains an important activity. The DH Policy Research Units in Economic Evaluation of Health and Care Interventions and Cancer Awareness, Screening and Early Diagnosis were commissioned to undertake a cost-effectiveness study of DH’s cancer symptoms awareness campaigns relating to colorectal and lung cancer. The study developed models of the natural history of these diseases and used evidence from the two regional pilot campaigns. Preliminary results suggest these interventions have the potential to be within the National Institute for Health and Clinical Excellence (NICE) threshold of cost effectiveness, although there are some major sources of uncertainty in the available evidence. Although the authors stress the limitations of these studies, they do demonstrate the potential to model the benefits of these campaigns and to estimate the extent to which they are an effective use of NHS resources.

Cancer does not discriminate campaign

3.23. To date the campaign has developed four specific health supplements aimed at improving awareness of cancer in the African, African-Caribbean, Asian and Irish communities living in England. With support of Black and Minority Ethnic (BME) led voluntary sector organisations, over 200,000 health supplements have been distributed across our target areas. Four cities (Nottingham, Birmingham, Leeds, and Leicester) and a London borough (Tower Hamlets) were chosen to pilot month long activities. Small grants were made available to support local organisations, community groups, and the voluntary sector to put on cancer awareness activities within the selected month. The first regional launch was in Nottingham on 19 September 2012, with 35 grants awarded providing a full calendar of events throughout September and October. The pilot campaign is due to end in February 2013, with a report due in March 2013.

3.24. The cancer and faith programme has developed a training package to train local people to become local cancer patient champions. The first course has been successfully delivered, and each champion will now have the resources and information to deliver cancer awareness workshops in their local areas.

3.25. The campaign has also teamed up with some leading cancer charities to develop awareness videos on breast cancer, bowel cancer, cervical cancer,
lung cancer, myeloma and prostate cancer. The videos are available to watch on the BME Cancer Voice website\(^\text{31}\).

**Developing and implementing a community-based prostate health clinic in Newham for hard to reach men**

3.26. DH, the National Cancer Action Team (NCAT) and Prostate Cancer UK worked with NHS Newham and Barts Health Care NHS Trust to pilot the Newham Prostate Health Drop-in Clinic at the Newham African-Caribbean Resource Centre in 2011. The clinic was an innovative model aimed at supporting the healthcare needs of men who often feel excluded from accessing healthcare support.

3.27. The clinic attempted to map itself on to the needs of the service user rather than the other way round. Men could self-refer and did not need an appointment to attend; opening hours were flexible and specialist nurses and doctors operated a one-to-one service offering information and support about all aspects of prostate health. Following on from a consultation, service users could access diagnostic investigations on site with a follow-up in secondary care if necessary. Blood could be taken for Prostate Specific Antigen (PSA) testing in clinic, and analysed at the acute Trust.

3.28. In a formal evaluation of the clinic undertaken by researchers at King’s College London\(^\text{32}\), men scored the clinic very highly in terms of access and convenience. They talked about the bespoke clinic with friends, with 25% of men who visited the clinic doing so because of word-of-mouth referrals. This approach complemented the advertising campaign which promoted the clinic among the local community.

3.29. The pilot clinic provided a safe environment for these men to express fears or concerns that were not being addressed elsewhere: many symptomatic men who visited the clinic said that they would not have visited a GP citing a number of reasons, including fear, embarrassment or simply not thinking their worries were warranted.

3.30. Nine new diagnoses of early stage prostate cancer were made, along with diagnoses of other conditions, suggesting men used the clinic for accessible medical advice. Another important finding was that men attended the clinic

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\(^{32}\) [Evaluation of a Community-based Prostate Health Clinic in London](http://www.kcl.ac.uk/nursing/research/programmes/PatientCarerExperience/Evaluation-of-a-Prostate-Health-Clinic---report.pdf)
with the intention of being tested rather than wanting to hear about the advantages and disadvantages of being tested before deciding, raising important issues about the concept of informed choice.

3.31. The evaluation also concluded that further community-based prostate clinics could be introduced and evaluated to determine optimal service models and locations to reach men reluctant to use traditional primary care services.

3.32. The learning gained from the pilot is being shared widely with stakeholders both within London and across England. The clinic won the *Helping people live longer* award at the Quality in Care Programme Excellent in Oncology Awards 2012.

**Cancer symptoms survey**

3.33. In line with our work to achieve earlier diagnosis of cancer we are supporting a survey co-funded by CRUK and NCAT to examine the nature and duration of symptoms experienced by people with cancer before their diagnosis.

3.34. The survey was 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 was sent to over 4,000 people who were diagnosed with one of between 20 - 25 cancer types.

3.35. The results of the survey are due to be published shortly but, in the meantime, they have been used to inform the development of the messaging around symptoms for the “multiple cancers” campaign.

**Supporting general practitioners to assess patients more effectively and improve opportunities for earlier investigation and diagnosis**

**Clinical decision support tools**

3.36. In 2012-13, Macmillan Cancer Support, with DH funding, is piloting an electronic cancer decision support tool for GPs to use in their routine practice. They are intended to help GPs identify patients whom they might not otherwise refer urgently for suspected cancer. The new electronic version is based on risk calculators developed by Professor Willie Hamilton’s Risk Assessment Tool (RAT, based on the CAPER studies) and Q-Cancer© (developed by ClinRisk) and will be promoted by Cancer Networks and tested further. This work builds on earlier pilots led by NCAT and Macmillan Cancer Support.
Significant Event Audits (SEAs)

3.37. The Royal College of General Practitioners (RCGP), in partnership with NCAT and Macmillan Cancer Support, is piloting a project to offer GPs peer review of completed cancer Significant Event Audits (SEAs) with an assessment report that can be included in their appraisal or revalidation portfolios. Initially GPs in 13 Cancer Networks have been invited to take part.

Primary care engagement pilot

3.38. CRUK and NCAT are collaborating to develop a long-term sustainable plan to engage all GP practices in England. Starting with a limited number of practices, the programme provides intensive support and engagement through a clinical and non-clinical team. The focus is initially on early diagnosis but the intention is to extend this type of support across the whole cancer patient pathway.

On-line learning for GPs

3.39. An on-line learning tool for GPs supported by DH and developed by BMJ Learning was launched in September, with the first of four modules. This resource covers relevant topics on cancer and earlier diagnosis that are of value to primary care and offers accredited professional development. This is one of a number of such resources available for GPs.

Cancer Network GP leads

3.40. GP leads are working with practices on early diagnosis of cancer, using the practice profiles, audit and SEAs, delivering training and education events and raising the importance of early diagnosis of cancer with commissioners and primary care teams. The University of Durham has been commissioned to evaluate this activity. The interim analysis showed that there has been engagement by Network teams and action aimed at quality improvement, with over half (4,191) of the practices in England. Engagement has been underpinned by GP practice profiles. Participation has been highest for activities linked to local, regional or national symptom awareness campaigns, including practice preparation for the public response. Primary care cancer audit and SEA analysis were also widely taken up. The engagement with practices has varied between Cancer Network (13% - 100%).

33 http://learning.bmj.com/learning/module-intro/.html?moduleId=10036231
GP access to diagnostic tests

3.41. Work has been underway to support more direct access for GPs to four priority areas of diagnostic tests set out in IOSC, including:

- publication of best practice referral pathways to support GPs with direct referral to specific diagnostic tests for the assessment of particular symptoms where cancer may be suspected but urgent GP referral (two week wait) is not applicable\(^\text{34}\)
- DH and the Health and Social Care Information Centre (HSCIC) launching the new data collection, the Diagnostic Imaging Dataset. A major driver for the dataset relates to earlier diagnosis of cancer, although the collection is not exclusively focused on imaging relating to cancer (see Chapter 1).

Endoscopy

3.42. One of the key priorities this year has been to focus on increasing endoscopy activity in response to 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. DH has estimated that over five years the NHS needs to plan for a 10-15\% year on year increase in lower gastro-intestinal (GI) endoscopy activity. Work has been underway to support improving endoscopy capacity, via:

- a programme of work led by NHS Improvement to support service improvement interventions and improved capacity and productivity (in conjunction with NHS Interim Management and Support (NHS IMAS). The programme, which runs until March 2013, builds upon work undertaken by NHS Improvement, which involved a rapid review of 14 endoscopy sites to understand issues and challenges that sites were facing in planning for an increase in demand (published March 2012)\(^\text{35}\)
- a series of capacity and planning workshops, organised by the Joint Advisory Group on GI endoscopy in collaboration with the NHS Bowel Cancer Screening Programme, to empower and enable endoscopy teams to provide the optimal business case for increased capacity and to ensure they are using the resource available most effectively.

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\(^{34}\) DH (April 2012) Direct Access to Diagnostic Tests for Cancer: Best Practice Referral Pathways for General Practitioners

\(^{35}\) NHS Improvement (March 2012) Rapid Review of Endoscopy Services
In many areas, improving endoscopy capacity is central to ensuring people receive diagnostic tests in good time. The NHS Operating Framework 2012-13 introduced an expectation that less than 1% of patients should wait six weeks or longer for a diagnostic test, which includes endoscopy tests. Organisations reporting high proportions of patients waiting six weeks or longer for endoscopy need to take action, which may include capacity and demand planning, in order to reduce these waits as quickly as possible. Table 3.1 shows those acute Trusts reporting over 5% of patients waiting six weeks or more as at the end of October 2012.

Table 3.1 Acute trusts with highest percentages of 6 week waits for four key endoscopy tests - October 2012

<table>
<thead>
<tr>
<th>Provider</th>
<th>Total number of patients waiting for an endoscopy test at end of October 2012</th>
<th>Number of endoscopy waits reported as 6 weeks or longer at end of October 2012</th>
<th>Percentage of endoscopy waits reported as 6 weeks or longer</th>
</tr>
</thead>
<tbody>
<tr>
<td>University Hospitals Bristol NHS Foundation Trust</td>
<td>1,143</td>
<td>613</td>
<td>53.6%</td>
</tr>
<tr>
<td>Oxford University Hospitals NHS Trust</td>
<td>1,052</td>
<td>184</td>
<td>17.5%</td>
</tr>
<tr>
<td>Hampshire Hospitals NHS Foundation Trust</td>
<td>856</td>
<td>149</td>
<td>17.4%</td>
</tr>
<tr>
<td>Wirral University Teaching Hospital NHS Foundation Trust</td>
<td>889</td>
<td>113</td>
<td>12.7%</td>
</tr>
<tr>
<td>North West London Hospitals NHS Trust</td>
<td>84</td>
<td>10</td>
<td>11.9%</td>
</tr>
<tr>
<td>Sandwell And West Birmingham Hospitals NHS Trust</td>
<td>1,064</td>
<td>90</td>
<td>8.5%</td>
</tr>
<tr>
<td>Guy's And St Thomas' NHS Foundation Trust</td>
<td>618</td>
<td>46</td>
<td>7.4%</td>
</tr>
<tr>
<td>Bradford Teaching Hospitals NHS Foundation Trust</td>
<td>750</td>
<td>53</td>
<td>7.1%</td>
</tr>
<tr>
<td>University Hospitals Of Morecambe Bay NHS Foundation Trust</td>
<td>849</td>
<td>59</td>
<td>6.9%</td>
</tr>
<tr>
<td>Poole Hospital NHS Foundation Trust</td>
<td>415</td>
<td>28</td>
<td>6.7%</td>
</tr>
<tr>
<td>King's College Hospital NHS Foundation Trust</td>
<td>331</td>
<td>22</td>
<td>6.6%</td>
</tr>
</tbody>
</table>
3.44. So far in 2012-13, at national level the NHS has reported a significant increase in colonoscopy and flexible sigmoidoscopy activity. In the period April to October 2012, the NHS has reported a 15.5% increase in colonoscopy activity and a 12.1% increase in flexible sigmoidoscopy activity, compared with the same period in 2011\textsuperscript{36}.

Cancer waiting times

3.45. Speedy diagnosis and treatment of cancer is an important factor in improving outcomes. Because of these benefits, the maximum waiting time requirements for cancer patients are included in the Operating Framework for the NHS in England for 2012-13\textsuperscript{37} and, in the case of the All Cancer Two Week Wait are a patient’s right to access services within maximum waiting times set out in the NHS Constitution\textsuperscript{38}.

Overall performance

3.46. National performance against the cancer waiting times measures set in the Operating Framework for the NHS in England 2012-13 has been sustained – although there remain concerns in a few Trusts which consistently fail on the operational standards. Table 3.2 shows both the levels of achievement for Quarter Two 2012-13 and the levels the NHS is expected to meet (the operational standards). The operational standards make allowances for the

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|c|}
\hline
Provider & Total number of patients waiting for an endoscopy test at end of October 2012 & Number of endoscopy waits reported as 6 weeks or longer at end of October 2012 & Percentage of endoscopy waits reported as 6 weeks or longer \\
\hline
Gloucestershire Hospitals NHS Foundation Trust & 1,153 & 76 & 6.6% \\
North Bristol NHS Trust & 434 & 28 & 6.5% \\
Royal Surrey County Hospital NHS Foundation Trust & 579 & 34 & 5.9% \\
\hline
\end{tabular}
\caption{Table 3.2: Endoscopy wait times}
\end{table}

\textsuperscript{36} Source: Department of Health, Diagnostic Test Waiting Times and Activity Statistics (DM01) April 2012 - October 2012
\textsuperscript{37}http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf
\textsuperscript{38}http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132958.pdf
fact that not all patients may wish to be seen or treated within the required
time, and that there will be a portion of patients for whom it would not be
clinically appropriate to undergo treatment within these timescales.

Table 3.2 Cancer waiting times statistics Quarter 2 2012-13

<table>
<thead>
<tr>
<th>Waiting Time Measure</th>
<th>Operational Standard</th>
<th>Quarter Two 2012-13 Achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cancer two week wait</td>
<td>93%</td>
<td>95.4%</td>
</tr>
<tr>
<td>Two week wait for breast symptoms (where cancer was not initially suspected)</td>
<td>93%</td>
<td>95.7%</td>
</tr>
<tr>
<td>Two month (62 day) urgent GP referral to first treatment wait for all cancers</td>
<td>85%</td>
<td>87.3%</td>
</tr>
<tr>
<td>62 day wait for first treatment following referral from an NHS cancer screening service</td>
<td>90%</td>
<td>94.9%</td>
</tr>
<tr>
<td>62 day wait for first treatment following a consultants decision to upgrade the priority of the patient</td>
<td>None set; this has been left for local implementation.</td>
<td>93.2%</td>
</tr>
<tr>
<td>One month (31 day) diagnosis to first treatment wait for all cancers</td>
<td>96%</td>
<td>98.4%</td>
</tr>
<tr>
<td>31 day wait for second or subsequent treatment – surgery</td>
<td>94%</td>
<td>97.5%</td>
</tr>
<tr>
<td>31 day wait for second or subsequent treatment – anti-cancer drug regimens</td>
<td>98%</td>
<td>99.8%</td>
</tr>
<tr>
<td>31 day wait for second or subsequent treatment – radiotherapy</td>
<td>94%</td>
<td>97.9%</td>
</tr>
</tbody>
</table>

Source: DH waiting times for suspected and diagnosed cancer patients, provider based
Changes and variations in urgent two-week wait referrals

3.47. Since the introduction of the all 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. The number of patients being first seen by a specialist at an English NHS provider following an urgent referral now stands at 306,011 (Quarter Two 2012-13), with over a million urgent referrals a year. Though the methods used to calculate these statistics have changed since the number of patients was first reported, there has been a major increase in patient numbers over the last eleven years.

62-day urgent GP referral to first treatment for all cancers and the 62-day wait for first treatment following referral from a cancer screening service

3.48. The NHS has maintained performance for the delivery of cancer waiting times over the last two years and since the publication of IOSC in 2011. As shown Figure 3.2, the NHS has met or exceeded the operational standards for 62-day urgent GP referral to first treatment for all cancers and the 62-day wait for first treatment following referral from a cancer screening service.

Figure 3.2 Proportion of patients receiving first definitive treatment within 62 days of an urgent GP referral for suspected cancer
Publication of more detailed statistics

3.49. Since Quarter Three 2011-12, DH has been publishing statistics at a more granular level for the one month (31-day) diagnosis to treatment and the two month (62-day) referral to treatment standards. These statistics provide data by the following tumour types; breast, lower GI, lung, skin and urological cancers, with a separate group for other cancers.

3.50. This additional information is intended to support patients in better understanding the quality of their care and in making informed choices. These statistics show variation between tumour types for NHS England. For example, the most recent published statistics (Quarter Two 2012-13) shows that 97.8% of patients referred urgently with suspected breast cancer were treated within 62 days. Conversely, only 79% of patients referred urgently for suspected lower gastrointestinal cancers were treated within 62 days. These variations were probably due to the relative complexities of some of the clinical pathways and different levels of choice between patient groups.

Other issues relevant to improving survival rates

Making sure older people have access to appropriate interventions

3.51. We have been concerned for some time that a number of older people may be receiving sub-optimal treatment for their cancer. This may be due to assumptions being made about an older person’s ability to tolerate treatment, in the absence of a full assessment of their health. Lack of practical support, such as transport or support with caring responsibilities, also presents a barrier to some older patients receiving treatment.

3.52. In 2010 we co-funded a two year pilot programme in partnership with Macmillan Cancer Support which aimed to improve access to appropriate cancer treatment for people over 70. The \textit{Improving Cancer Treatment, Assessment and Support for Older People Project} funded 14 NHS Trusts across five Cancer Networks (Merseyside and Cheshire, North East London, South East London, Sussex and Thames Valley). Participating NHS Trusts:

- tested and evaluated the use of Comprehensive Geriatric Assessment in clinical practice
- formed partnerships with voluntary sector organisations to ensure the practical support needs of older people with cancer were met
identified staff training and development needs which must be addressed to promote age equality and reduce age discriminatory practice.

3.53. Since May 2011, over 700 older cancer patients have been assessed using comprehensive geriatric assessment. The assessment provided objective information to inform treatment decisions, and also identified support needs which were addressed to ensure patients gained the maximum benefit from treatment. Each Cancer Network tested different models of care, where either a cancer specialist or an elderly care specialist led the assessment process. Patients who had practical support needs were referred to a local voluntary sector provider. Significant staff training needs were identified by each Cancer Network.

3.54. The project was completed in September 2012. The project report, which will include an number of key recommendations, will be published shortly. Early project findings demonstrate the benefits of engaging elderly care specialists as part of the cancer care team, and that comprehensive geriatric assessment is feasible in cancer services. More information can be found on the Macmillan Cancer Support website39.

**POI/NCEI project**

3.55. Working in partnership, the National Cancer Equality Initiative (NCEI) and the Pharmaceutical Oncology Initiative (POI) 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 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, using this analysis to predict behaviour.

3.56. The key finding of the report, published in February 201240, is that clinicians may over rely on chronological age as a proxy for other factors which are often but not necessarily associated with age, such as co-morbidities or frailty. This finding is in contrast to the perceptions of clinicians which is that factors such as comorbidity or frailty are more important than age itself. Based on this finding, the report has a series of recommendations for health

39 [www.macmillan.org.uk/geriatric oncology](http://www.macmillan.org.uk/geriatric oncology)
services, the professions, charities, researchers and the pharmaceutical industry, which are being taken forward through the NCEI.

**Men and cancer workshop**

3.57. Adjusting for women’s longer life expectancy, men are diagnosed with more cancers and have a higher mortality from cancer. There is an excess incidence of 16% and an excess mortality of 38% in men. In partnership with the NCEI, the Men’s Health Forum is holding a major workshop on men and cancer at the King’s Fund on 29 January 2013. This follows on from a workshop held at Leeds Metropolitan University in 2006. The key issues to be discussed at the workshop will include: symptom awareness and early diagnosis in men; bio-medical versus social/lifestyle explanations for gender differences in incidence; and case-studies of successful project work/research with men that help to define the next steps.

**Ensuring that everyone has access to appropriate treatment**

3.58. As we set out in IOSC, improvements in survival rates are dependent primarily on earlier diagnosis of cancer and ensuring that everyone has access to the right treatment, when they need it. The preceding paragraphs describe work in train in relation to older people and men, to improve access to treatment. Chapter 1 describes some of the data and analyses that we are producing to ensure that commissioners and providers know where intervention rates are sub optimal. A range of central initiatives are relevant to supporting the NHS in this regard. For example, the Department established a £300m fund in March of this year, to be operated by NHS Supply Chain, to bulk purchase medical equipment to achieve better prices for the NHS, including the purchase of radiotherapy equipment. This should help to make sure that patients have access to the latest advances in radiotherapy technology, such as Intensity Modulated Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT), and the NHS can keep up with the increasing demand for services.

3.59. The Mandate for the NHS for 2013-2015 makes clear the expectation that the NHS Commissioning Board is to make significant progress “in ensuring

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people have access to the right treatment when they need it” and “in reducing unjustified variation between hospitals in avoidable deaths, so that standards in all hospitals are closer to those of the best”.

Priorities for the coming year

3.60. Delivering on the ambition to improve cancer survival rates will a significant priority for next year, and will be one of the key areas for the Director for Reducing Premature Mortality (Domain 1) in the NHS CB. In order to deliver improvements, in addition to the priorities described in the previous chapter, it will be essential for work to continue to:

- raise awareness of cancer symptoms among the public and to encourage them to present promptly with persistent symptoms
- support GPs to refer appropriately
- ensure that secondary care has appropriate resources available for testing those with symptoms that are suggestive of cancer
- tackle unacceptable variations in curative treatment levels.
4. NHS Outcomes Framework Domain 2: quality of life for people with long-term conditions

Introduction

4.1. It is good news that people living longer and improvements in cancer survival rates mean that there are increasing numbers of cancer survivors. But we know that more needs to be done to minimise the possible late effects of treatment, to support cancer survivors to lead as healthy a life as possible for as long as possible and to make sure that services are as cost effective as possible, to enable them to cope with the increasing numbers. This chapter sets out progress in these areas.

Reducing possible late effects of treatment

Intensity Modulated Radiotherapy (IMRT)

4.2. In the first annual report we stated that targeted radiotherapy can reduce the risk of long-term damage for cancer patients and that Intensity Modulated Radiotherapy (IMRT) has the capability to reduce damage to normal healthy tissue leading to both improved cure rates and reduced side effects with the subsequent reduction in the need to manage long-term, serious toxicities. We said that while almost all treatment machines are capable of delivering IMRT, rates of activity against those recommended by the National Radiotherapy Implementation Group remained low.

4.3. A survey undertaken earlier this year\textsuperscript{43} identified that only four radiotherapy centres were delivering inverse planned IMRT at the recommended rate of 24% of all radical treatment\textsuperscript{44}.

4.4. In October, the Prime Minister announced a new radiotherapy innovation fund for 2012-13. The priority for this fund is to ensure that all centres have the capability to deliver IMRT at the expected rate from April 2013. Centres

\textsuperscript{43} Mayles WPM, Cooper T, Mackay R, Staffurth J, Williams M, \textit{Intensity-Modulated Radiotherapy Implementation in the UK}. Clin Oncol. 2012; 24:543-544
\textsuperscript{44} NRIG IMRT Guide to Commissioners Nov 2009: http://www.ncat.nhs.uk/radiotherapy/treatments
have been asked to bid against the fund and a programme of support visits to help providers implement actions plans is underway and a national training programme aimed at clinical teams will be delivered in 2013. This work is being led by NRIG, assisted by Cancer Research UK.

Image Guided Radiotherapy (IGRT)

4.5. A national programme is also underway to support the increased use of Image Guided Radiotherapy (IGRT). IGRT together with IMRT is fundamental to delivery of the National Radiotherapy Advisory Group recommended technical standard for radiotherapy of Four Dimensional (4D) adaptive radiotherapy. Technical guidance for the use of IGRT was published on the National Cancer Action Team (NCAT) website in September and a training programme is underway with training leads visiting all radiotherapy services in the country to support implementation of the guidance. Three leading physics services are supporting the radiotherapy physics quality assurance processes.

Proton Beam Therapy

4.6. In April this year, the Secretary of State for Health announced that that the Department of Health (DH) had set aside up to £250 million of public capital to be invested by the NHS in building Proton Beam Therapy facilities at The Christie Hospital in Manchester and University College London Hospital. These facilities will treat up to 1500 patients a year and the first is due to become operational from the end of 2017.

4.7. The programme will be nationally-led to ensure that services are developed as part of a fully integrated network of care, providing access for patients from all parts of the country and managing the impact on existing services, including protecting pathways to enable future expansion of services as necessary.

4.8. Until the national service becomes fully operational, high priority cases will continue to travel overseas for this treatment. In 2011-12, 79 patients went overseas for treatment and we expect to send 100 in 2012-13 increasing to 400 by the end of 2013-14.

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 current 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. Following a public consultation on plans for its operation, between October 2010 and January 2011, the Cancer Drugs Fund was launched on 1 April 2011. Over three years, the Cancer Drugs Fund is making £200 million available annually to support improved access to cancer drugs. This builds on £50 million of additional in-year funding that was allocated to Strategic Health Authorities to support improved access to cancer drugs in 2010-11.

4.11. Between October 2010 and the end of September 2012, this funding has helped over 23,000 cancer patients in England to access additional cancer drugs that can extend or improve life.

4.12. 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. The Chemotherapy Intelligence Unit based at the Oxford Registry is carrying out a national audit of Cancer Drugs Fund usage. Monthly data collection commenced in April 2012, with retrospective data also being collected for 2011-12. The analysis of this data will provide information on the duration of treatment received and the overall patient outcome in terms of survival. This information will become increasingly robust as greater patient numbers accrue. It is hoped that the outcome data from the Cancer Drugs Fund will offer valuable insights into the difference between outcomes observed in clinical trials and every day use in NHS practice.

4.13. The Government is continuing its work towards a new system of pricing for innovative medicines, where the price of a drug will be linked to its assessed value. Value-based pricing will bring the price the NHS pays more in line with the value that a new medicine delivers. The Government consulted on its proposals and, following the Government response in July 2011, DH has been taking forward a work programme to develop the weights for value-based pricing in collaboration with external experts and stakeholders. DH held an event in September 2012 to update stakeholders on the work, and will continue to engage with patients, clinicians, the NHS, taxpayers, industry and other interested parties as work progresses.
Survivorship

4.14. In the first annual report, we set out our plans to update the 2010 survivorship vision, to set out the evidence base for what services should be provided for cancer survivors in the future. That document, *Living with and beyond cancer: Taking action to improve outcomes*, is a joint initiative between Macmillan Cancer Support, DH and NHS Improvement, and is due to be published shortly.

4.15. It will report on the ways in which support can be offered to cancer patients along their whole patient pathway, and how that support can be provided in the most cost-effective way. The document pulls together good practice and offers new models of service delivery that can be commissioned and provided in the future. In particular, the document aims to improve survivorship by ensuring that all cancer patients are offered a package of advice, information and support, tailored to their on-going needs.

Patient Reported Outcome Measures (PROMs)

4.16. Last year, we reported on the piloting of Patient Reported Outcomes Measures (PROMs) for cancer survivors. The results from these pilots are part of the important new evidence now available about cancer survivors’ needs. The results are being published at the same time as this report.

4.17. Key messages from the pilot were:

- the response rate of 66% (3,300 out of 4,992) showed that people who survive cancer are willing to participate in such surveys, which provide very valuable data about cancer survivors’ health and wellbeing
- the presence of one or more long-term condition in addition to cancer was associated with a significantly lower quality of life
- people from the most disadvantaged geographical areas reported lower quality of life scores and lower scores on other measures
- 47% of patients reported a fear of a recurrence of their cancer, but this reduced the further the patient was away from first diagnosis
- 23% of patients reported moderate or severe problems with mobility and 21% had equivalent problems with everyday activities
- bowel and urinary problems affected a significant minority of patients living beyond a bowel or prostate cancer diagnosis. These patients
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reported a significantly lower quality of life score. More targeted support and rehabilitation may positively affect outcomes here

- quality of life scores were lower than those reported by the general population in the Health Survey for England (2008) and the General Practice Patient Survey (2011), though direct comparisons are difficult because of differences in the age of participants.

4.18. Following the success of the 2011 PROMs pilot of breast, prostate, colorectal and Non-Hodgkins Lymphoma survivors we are running:

- a pilot survey of other pelvic cancers (cervix, ovary, uterus and bladder) at 1, 2, 3 and 5 years post diagnosis

- a large scale national survey of colorectal patients across England (1-3 years post diagnosis).

Survey questionnaires will be sent out to relevant cancer survivors in January 2013.

Priorities for the coming year

4.19. A commitment has been made to ensure that all patients can get access to the appropriate cost-effective and safe innovative forms of radiotherapy. This will help to minimise long term side effects of treatment. NHS commissioners and providers will wish to consider the implications of the PROMs surveys and the recommendations of the forthcoming survivorship report.
5. NHS Outcomes Framework
Domain 3: helping people to recover from episodes of ill health or following injury

Introduction

5.1. The NHS has continued to make progress in improving quality of care provided during acute treatment for cancer, along with improvements in productivity. This chapter reports on progress in terms of reductions in bed days and emergency admissions, along with work undertaken centrally – by NHS Improvement and the National Cancer Action Team - to support improvements in quality and productivity.

Bed days

5.2. Progress continues to be made in reducing bed days. Although we have only provisional data for 2011-12, and the estimates are likely to be revised upwards, the bed days have reduced from 4,447,917 in 2010-11 to 4,332,511 in 2011-12 – despite an increase in episodes of care from 2,146,135 to 2,285,861. The provisional figures in relation to emergency bed days are also positive – with a reduction from 2,742,917 in 2010-11 to a provisional figure of 2,683,499 in 2011-12. It is important to note that these changes are occurring in the context of a rising incidence of cancer. However, there is a long way to go to deliver the reductions that the National Audit Office estimated could be achieved, and therefore the productivity improvements needed to fund new cancer services.

Enhanced Recovery Partnership

5.3. The Enhanced Recovery (ER) Partnership has continued to build on progress in promoting the spread and adoption of enhanced recovery. Good progress has been made in reducing length of stay across the following procedures: cystectomy, prostatectomy, colectomy, rectal surgery and abdominal and
vaginal hysterectomy. Despite rises in activity for almost all of these procedures, there were nearly 70,000 fewer bed days for these procedures in 2010 than in 2008-9. Readmission rates for organisations known to have implemented enhanced recovery for these procedures are not significantly higher or lower than the national average. Further savings are still possible for these specialties, from further implementation of enhanced recovery, which could amount to 120,000 bed days per year.

5.4. Consensus is growing for the transferability of enhanced recovery principles to other elective and non-elective surgical procedures. These include thoracic, hepatobiliary, upper gastrointestinal (GI) surgical procedures and emergency procedures in the original specialities, with the aim of continuing to reduce length of stay and unnecessary bed days. HES 2010-11 analysis identifies variation in length of stay with these procedures. Future testing of transferability of ER principles will identify what can be achieved and the levels of ambition.

5.5. The applicability of ER principles to other acute illness conditions is being scoped by a number of providers who are in the early testing phase to identify the scope for improvement and levels of ambition.

5.6. Benchmarking data on ER metrics, a toolkit for local audit of ER implementation and brief guidance for commissioners are available at: www.improvement.nhs.uk/enhancedrecovery/

5.7. The ER Partnership working with a national enhancing patient experience working group have developed a generic patient information leaflet My roles and my responsibilities in helping to improve my recovery. The leaflet has been designed, tested and evaluated by patients for patients in order to give practical step by step advice to anyone prior, during and after surgery. It can be used alongside existing patient information to support key messages and encourage patients to take an active role in their preparation and recovery from surgery.

5.8. Over 100,000 hard copies of the leaflet have been ordered and distributed to approximately 40% of acute provider organisations. The leaflet has been evaluated and patients report that it has helped them understand their role
and feel more confident and prompted them to ask questions and be more proactive in their own recovery. The leaflet has been promoted widely by charitable organisations, Royal Colleges and NHS Choices, and its use is being further evaluated with patient groups to determine the applicability of messages to all patients with acute illness. The leaflet can be accessed online from the ER Partnership and NHS Choices websites.

Emergency and urgent care

Whole hospital emergency partnership

5.9. A whole hospital approach to urgent/emergency care is being taken in a unique partnership with Derby Hospitals NHS Foundation Trust to focus on reducing unnecessary emergency admissions to hospital and to reduce the length of time patients have to stay in hospital.

5.10. The partnership, which started in September 2012, will test the following hypothesis: 25% of bed days can be reduced and length of stay can be reduced by 10-50%, dependent on specialty, for 80% of patients, with demonstrable improvements in patient experience and outcomes. The work will have a phased approach, with phase one focusing on unplanned surgery from emergency admission/assessment units throughout the pathway.

An integrated approach to urgent and emergency care: sharing knowledge – delivering benefits

5.11. NHS Improvement has been working with a small number of acute hospital Trusts to understand the complexity of urgent and emergency care admissions. The learning from this work has been developed into a new publication An integrated approach to urgent and emergency care - sharing knowledge – delivering benefits, which focuses on bringing together the key generic messages in relation to urgent and emergency care and, in particular, on the size of the problem, understanding the real issues and the variation in service provision. It offers some tried and tested solutions on how to reduce admissions and unnecessary lengths of stay for patients. It can be accessed at www.nhsimprovement.nhs.uk

45 http://www.improvement.nhs.uk/documents/er_my_role.pdf
Breast surgery day case/one night stay

5.12. Progress on the sustainability of major breast surgery (excluding reconstruction) as a day case/one night stay has continued. The original hypothesis to reduce length of stay by 50% and release 25% of unnecessary bed days for 80% of major breast surgery (excluding reconstructions) has been exceeded.

5.13. The mean length of stay has reduced from 2.35 days to 1 day overall in 2011-12. Day cases and overnight stays now make up 81% of all procedures compared with only 47% in 2006-07, and 96% of patients in 2010-11 were admitted on the day of surgery compared with 69% in 2006-7. Bed days continue to reduce year on year with a further reduction of 17,008 in 2011-12. Patient feedback of their experience of the pathway remains extremely positive, with strong clinical engagement evident.

5.14. 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 19%, 28 Trusts have less than 10% of their patients having LOS of more than one night. 10 Trusts still have 40% or more of their patients having LOS of more than one night and this is where efforts should continue to be concentrated in the coming year.

Improving the quality of surgery

Surgical training programmes

5.15. Nationally there has been an increase in the adoption of laparoscopic colorectal surgery during the past year. Provisional Hospital Episode Statistics (HES) analysis for April-June 2012 shows that 40% of all elective resections were undertaken laparoscopically, an increase from 34% in 2010-11. At Trust level, 14 Trusts are reporting low levels of laparoscopic surgery (less than 20% of resections). This is a substantial improvement from 2010-11 when 25 Trusts were reporting at this level.

5.16. The national training programme for laparoscopic surgery (LAPCO) provides training for colorectal consultants in England and has now signed off 39 trainees. A further 40 trainees are in the sign-off process and 56 are
currently in training. To ensure the highest quality of training LAPCO has developed a successful train the trainer course. It is projected that 54 of the 67 trainers within LAPCO will have attended by March 2013. The focus for the rest of this financial year is to support all registered trainees to progress through their training and reach the requirements to achieve sign off.

5.17. During the last year an economic analysis of the programme was undertaken by Imperial College. This showed that the predicted cost saving of the programme is £18m. This is largely due to a more rapid learning curve for this technique and a lower level of complications from LAPCO trainees compared to self-taught trainees.

5.18. The Low Rectal Cancer Development Programme (LOREC) aims to improve cancer outcomes and quality of life for patients with low rectal cancers. After a successful pilot the Programme is now being offered to all colorectal multi-disciplinary teams (MDTs) in England during 2012-13.

5.19. The central part of the Programme is the expert faculty workshops which help MDTs to improve the decisions they make on low rectal cancer patients. They involve surgeons, radiologists, pathologists, oncologists and nurse specialists. In addition the programme offers cadaveric courses as well as mentoring in a different method of excision of low rectal cancers, the extra levator abdominoperineal excision (ELAPE). The Programme also now provides magnetic resonance imaging (MRI) workshops in order to support radiologists in optimising MRI techniques for these patients.

Robotic prostatectomy framework

5.20. Guidance on the development and commissioning of robotic surgery in England, particularly robotic prostatectomy, was published on the British Association of Urological Surgeons website in December 201246.

Improving the effectiveness of chemotherapy

5.21. We have been working with a group of experts to develop the right mechanisms to ensure patients have rapid access to new molecular

diagnostic tests for cancers as they become available. In the summer, we shared with key stakeholders proposals for the development of a commissioning and funding structure to enable the efficient delivery of high quality molecular diagnostic testing through centres of excellence. Those proposals will now be put formally to the NHS Commissioning Board (NHS CB), but we have begun to test the NICE diagnostic review process for these types of tests and the relevant Royal Colleges are beginning to work on the development of guidance for tests and laboratories.

Peer review

5.22. In 2011-12 the national cancer peer review programme completed its third round of reviews which incorporated an annual self-assessment by teams with the Chief Executive of the service provider endorsing their report. Work to ensure improved sustainability of the programme has been introduced. Services that demonstrated previous high performance have received less external assessment whilst maintaining their internal governance. The internal governance arrangements within Trusts have become more robust through the internal validation process.

5.23. More patients and carers have accessed the peer review reports, but work is still required to enable patients and their carers to use self-assessment to inform choice on teams and services with confidence. A key area of development for the peer review programme is a public website to enable easier access to the peer review reports for patients and carers.

5.24. The peer review programme now reviews the quality of 1841 clinical cancer services/teams: 1245 tumour MDTs, 273 tumour network groups, along with services for radiotherapy, children’s cancer, cancer research networks, rehabilitation and complementary therapy.

5.25. The use of clinical lines of enquiry has been extended to six tumour types: breast, lung, colorectal, upper GI, gynaecology and head and neck services. This has been received well by clinical teams and has moved the focus of peer review towards clinical outcomes. In addition, peer review has started to use service profiles for breast and colorectal services, developed by the National Cancer Intelligence Network (NCIN), as a basis for the lines of enquiry and will adopt this for other teams when they become available.
5.26. The 2011-12 national overview shows that some teams and services continue to achieve very high levels of compliance with the measures; when considering all of the 1245 MDTs and 273 Network site specific groups (NSSGs), 484 (32%) achieved compliance with over 90% of the measures. The programme has however again highlighted some significant challenges. There remains a group of significant outliers and work needs to be done to address these services. In some cases compliance could be achieved through local effort, and without the need for additional resource. In other cases commissioners will need to consider whether it is practical for a team to achieve full compliance, or whether two or more neighbouring teams should be merged to achieve sustainability both of workforce and throughput of patients.

5.27. The peer review programme continues to work with the Care Quality Commission (CQC) sharing information about the poor performing teams and Trusts, and providing regular updates on any immediate risks identified through peer review. The findings of the peer review process inform the CQC Quality and Risk Profiles of organisations which are used to monitor on-going compliance with legal registration standards.

5.28. Further work is currently underway to ensure the continued sustainability of the programme while maintaining appropriate quality assurance, public confidence and patient information.

5.29. Over the coming year the programme will be working to reduce further the structure and process measures and focus more on outcomes, incorporating national audit data where available, and aligning to NICE Quality Standards. Changes will also be required to ensure the measures accommodate the changes within the network structures and ensuring the programme continues to review across the full patient pathway.

5.30. As part of overall support for commissioners, The Manual for Cancer Services measures are now an integral part of the service specifications, and compliance against the measures identified as part of the performance indicators.
Priorities for the coming year

5.31. The NHS CB has yet to determine its priorities for 2013-14, but the evidence suggests that there is further scope to improve quality and productivity in terms of hospital stays and emergency admissions, and so this could be an important area for the new improvement body within the NHS CB. In addition, the NHS CB will be working on new arrangements for molecular diagnostic tests for cancers.
6. NHS Outcomes Framework
Domain 4: improving experience of care

Introduction

6.1. We were delighted to see the significant improvements between the 2010 cancer patient experience survey and the 2011-12 survey. But this masks significant variation around the country, and there is scope across the board for further improvements. This chapter describes the results of the latest survey, along with activity to improve patient experience.

Cancer patient experience survey

6.2. The national\textsuperscript{47} and Trust level\textsuperscript{48} reports of the 2011-12 cancer patient experience survey (CPES) were published in August 2012. 71,793 patients completed a questionnaire with an overall national response rate of 68%, up by 1% on the 2010 survey. There was considerable variation in response rates, with the highest at 79% and the lowest at 45%. On most questions in the 2011-12 survey, scores have improved, which is a major achievement considering Trust level reports were issued in January 2011 and this latest survey covers patients from September 2011. The most significant increases in positive scores were on information and communication issues are shown in Table 6.1.

Table 6.1 Questions in the 2011-12 CPES with the most significant increases in positive scores

<table>
<thead>
<tr>
<th>Question</th>
<th>2010</th>
<th>2011-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q14: Patient given written information about the type of cancer they had</td>
<td>66%</td>
<td>69%</td>
</tr>
<tr>
<td>Q20: Patient given the name of a Clinical Nurse Specialist in charge of their care</td>
<td>84%</td>
<td>87%</td>
</tr>
</tbody>
</table>

\textsuperscript{48} [http://www.quality-health.co.uk/2012cancerreports.html](http://www.quality-health.co.uk/2012cancerreports.html)
6.3. Nine new questions were included in the 2011-12 survey. A new overarching question asking patients to rate their overall care came out very high, with 88% of patients rating their care “excellent” or “very good”. Although this is a high score, results from individual Trusts show there is significant variation in the proportion of patients rating their care as excellent or very good – 94% in the highest Trust to 64% in the lowest.

6.4. Three new questions were asked about research, with 33% of patients saying that taking part in research had been discussed with them. Of these, 95% were glad to have been asked. Of the patients who were not asked about research, 53% said they would have liked to have been asked.

6.5. Other new questions had less positive results, such as all staff asked patients what name they preferred to be called (56% - highest Trust 82%, lowest 24%) and patient offered written assessment and care plan (24% - highest Trust 49%, lowest 5%), but these provide a good baseline for future surveys.

### Ten best and ten poorest performing Trusts

6.6. Based on analysis of the 2011-12 CPES data, Macmillan Cancer Support published the ten best and ten worst performing NHS Trusts in England in August 2012. The ten best performing Trusts, ranked by the number of times they appeared in the top 20% of responses to a specific question in the survey, are shown in Table 6.2.

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<table>
<thead>
<tr>
<th>Question</th>
<th>2010</th>
<th>2011-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q26: Hospital staff told patient they could get free prescriptions</td>
<td>68%</td>
<td>73%</td>
</tr>
<tr>
<td>Q33: Patient given written information about the operation</td>
<td>68%</td>
<td>73%</td>
</tr>
</tbody>
</table>

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49 2011-12 National Cancer Patient Experience Survey – League table and tumour group variations (Macmillan Cancer Support, August 2012)
http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Patientexperiencesurvey2012.pdf
Table 6.2 Top ten best performing Trusts, ranked by the number of times they appear in the top 20% of responses to a specific question in the 2011-12 CPES

<table>
<thead>
<tr>
<th>Rank</th>
<th>Trust</th>
<th>Times in top 20%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Harrogate and District NHS Foundation Trust</td>
<td>55</td>
</tr>
<tr>
<td>2</td>
<td>South Tyneside NHS Foundation Trust</td>
<td>55</td>
</tr>
<tr>
<td>3</td>
<td>Papworth Hospital NHS Foundation Trust</td>
<td>46</td>
</tr>
<tr>
<td>4</td>
<td>Northumbria Healthcare NHS Foundation Trust</td>
<td>44</td>
</tr>
<tr>
<td>5</td>
<td>Gateshead Heath NHS Foundation Trust</td>
<td>42</td>
</tr>
<tr>
<td>6</td>
<td>Chesterfield Royal Hospital NHS Foundation Trust</td>
<td>37</td>
</tr>
<tr>
<td>7</td>
<td>Barnsley Hospital NHS Foundation Trust</td>
<td>37</td>
</tr>
<tr>
<td>8</td>
<td>St Helens and Knowsley Teaching Hospitals NHS Trust</td>
<td>36</td>
</tr>
<tr>
<td>9</td>
<td>Liverpool Heart and Chest Hospital NHS Foundation Trust</td>
<td>36</td>
</tr>
<tr>
<td>10</td>
<td>Tameside Hospital NHS Foundation Trust</td>
<td>35</td>
</tr>
</tbody>
</table>

6.7. The ten poorest performing Trusts, ranked by the number of times they appeared in the bottom 20% of responses to a specific question in the survey are shown in Table 6.3.

Table 6.3 Ten poorest performing Trusts, ranked by the number of times they appeared in the bottom 20% of responses to a specific question in the 2011-12 CPES

<table>
<thead>
<tr>
<th>Rank</th>
<th>Trust</th>
<th>Times in bottom 20%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Imperial College Healthcare NHS Trust</td>
<td>56</td>
</tr>
<tr>
<td>2</td>
<td>Whipps Cross University Hospital NHS Trust</td>
<td>50</td>
</tr>
<tr>
<td>3</td>
<td>King’s College Hospital NHS Foundation Trust</td>
<td>45</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Rank</th>
<th>Trust</th>
<th>Times in bottom 20%</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>The Princess Alexandria Hospital NHS Trust</td>
<td>42</td>
</tr>
<tr>
<td>5</td>
<td>North West London Hospitals NHS Trust</td>
<td>41</td>
</tr>
<tr>
<td>6</td>
<td>University College Hospital London NHS Foundation Trust</td>
<td>41</td>
</tr>
<tr>
<td>7</td>
<td>Ealing Hospital NHS Trust</td>
<td>41</td>
</tr>
<tr>
<td>8</td>
<td>Newham University NHS Trust</td>
<td>40</td>
</tr>
<tr>
<td>9</td>
<td>Barking, Havering and Redbridge University Hospitals NHS Trust</td>
<td>39</td>
</tr>
<tr>
<td>10</td>
<td>North Middlesex University Hospital Trust</td>
<td>38</td>
</tr>
</tbody>
</table>

6.8. To accompany their analysis, Macmillan Cancer Support also published a top tips guide to improving cancer patient experience\(^{50}\). The guide aims to share practical tips and examples of good practice in order to drive up the quality of care for people living with cancer.

**Cancer patient survey by equality group**

6.9. Data by equality group from the 2010 and 2011-12 surveys have been combined in an attempt to give the data more power. Although the analysis did not produce any new findings, it did confirm the finding from 2010 that there are many real differences across equality groups, such as:

- 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

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\(^{50}\) Improving cancer patient experience – A top tips guide (Macmillan Cancer Support, August 2012)  
[http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Patientexperiencesurvey_Toptipsguide.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Patientexperiencesurvey_Toptipsguide.pdf)
• patients with mental health conditions and/or a learning disability were more likely to feel treated as "a set of cancer symptoms"
• women were more likely to feel their treatment lacked respect, dignity and sufficient privacy
• men were less likely to be given a name of a CNS who would be in charge of their care.

6.10. The National Cancer Equality Initiative continues to highlight these issues, sharing the issues and best practice in tackling them with Cancer Networks.

Cancer patient experience survey 2012-13

6.11. The 2012-13 survey (ROCR/OR/2158/FT6/001MAND - 212/023) will cover inpatient and day case patients over the period 1 September 2012 to 30 November 2012. Trusts will identify eligible patients in December 2012 and questionnaires are likely to be sent out towards the end of January 2013. We expect the national and Trust level reports to be published in summer 2013. From April 2013, responsibility for the survey will move to the NHS Commissioning Board.

Other survey activity

6.12. Following on from the radiotherapy question in the national cancer patient experience survey, the National Cancer Action Team (NCAT) commissioned a bespoke survey to understand the experience and needs of radiotherapy patients. The survey is still in progress, but is expected to finish by the end of 2012. So far over 19,000 patients have completed and returned a questionnaire, a response rate of 56%. 69% of radiotherapy patients had 10 or more visits to their radiotherapy service. 96% felt they were treated with dignity and respect, and 98% felt the amount of information received was enough. 92% felt they were treated as a person rather than as a collection of cancer symptoms. However, the survey also showed that there are opportunities for improvement in post treatment care. After their treatment had finished, 12% of radiotherapy patients did not know who to contact and 21% said they did not know what to expect next.

6.13. NCAT also commissioned a survey of access to radiotherapy services and clinic opening times. The survey is nearly complete, and has a response rate of 76%. The results show that patients are overwhelmingly in support of extended hours for radiotherapy clinics, a model suggested by the National Radiotherapy Advisory Group. Over 70% of patients would be willing to attend for an early morning or late evening appointment, and over 90% would be prepared to attend for treatment on Saturday and Sunday and 85% on
Bank Holidays. There is little significant variation in these results across England. However, only 34% of patients were always offered a choice of appointment, with 42% saying they were never offered a choice. Although these results point to greater opportunity for extended working, greater patient choice and increased efficiency, changing the provision of the service would require out of hours care for a wide range of services that support patients in radiotherapy treatment, such as pharmacy, pathology, and radiology. Any planning within Trusts would therefore need to take account of these services to ensure a safe overall service.

Work to improve patient experience

Information Prescriptions

6.14. The two-year cancer Information Prescriptions (IP) implementation programme, a partnership between NCAT, Macmillan Cancer Support and Cancer Research UK, is due to conclude at the end of December 2012. Since November 2010, 70% of acute Trusts in England have been offered support from a national team of IP facilitators in implementing IPs for cancer patients and their carers. The team has worked with over 1,500 multi-disciplinary teams (MDTs) in 110 acute Trusts across England and anticipate that over half of these MDTs will be routinely issuing IPs for their cancer patients by the end of the programme.

6.15. MDTs bring together staff with the necessary knowledge, skills and experience to ensure high quality diagnosis, treatment and care for patients with cancer. The period up to 2012 has been about delivery, ensuring that patients are offered high quality, accessible and relevant information that is tailored to their needs and circumstances at every point of their cancer journey. The results of the 2011-12 CPES indicate significant improvements in the scores for patient information related questions. Successful Trusts have proactively used the results of the survey as a key driver and have integrated their implementation of IPs with other improving patient experience related initiatives. Supporting personalised information in cancer services demonstrates that it is possible to deliver personalised information with appropriate content, systems, training and support.

Connected

6.16. Since the start of the Connected national advanced communication skills training programme, some 15,000 senior clinicians have been trained, with 84% saying they would definitely recommend the course to other colleagues and a further 13% saying they probably would. It has proved its value for
clinicians from different settings with a majority of those trained operating in settings other than cancer for much of their work.

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

6.17. The assessment and feedback tool to support cancer MDTs is nearing completion. MDT-FIT is being developed by Green Cross Medical, a group of cancer health professionals and academic researchers. Further testing has demonstrated that the tool is acceptable across all MDT types, including specialist and rare tumour teams as well as for teams working across multiple sites.

6.18. Teams who have tested the pilot version identified, on average, eight actions across a range of aspects of team working, many of which were implemented soon after participation in the MDT-FIT process. A web based platform to support teams using MDT-FIT is under development and a pilot roll-out is currently being undertaken across a number of Trusts within the same Network prior to wider roll-out beginning in the Spring of 2013.

**Quality in Nursing**

6.19. NCAT has launched a quality improvement toolkit which aims to improve the experience of patients undergoing treatment for cancer in England. The toolkit aims to address specific issues around the experience of nursing care identified in the 2010 and 2011-12 surveys. Full details of the tool can be found at [www.candocancercare.co.uk](http://www.candocancercare.co.uk).

6.20. The 2010 and 2011-12 surveys showed significant variance in the reported experiences of patients who had received chemotherapy. A survey of chemotherapy patients has been commissioned to help understand this group’s experiences in more detail. This chemotherapy survey has been designed and tested by members of the National Chemotherapy Implementation Group, patient representatives and members of the Quality in Nursing Steering Group. The survey covers questions on the patients’ experience before, during and after their chemotherapy treatments. Data collection is taking place between October and December 2012 and we expect that results from the survey will be published in early 2013.

6.21. NCAT is also working with cancer charities and key stakeholders from the cancer nursing community to calculate optimum caseloads for the cancer CNS using lung and colorectal pilot tumour groups. The output from this project will be an optimum caseload calculator which details the nursing
interventions at each stage of the pathway. The outcomes of this work will be available on the Cancer Commissioning Toolkit from January 2013.\(^5\)

6.22. Building on lessons learned from the 2011 chemotherapy census pilot, NCAT has designed a national chemotherapy census to collect workforce data on the number and type of nurses at Agenda for Change bands 5-9 delivering chemotherapy in ambulatory care settings. The 2012 census will enable Trusts to compare themselves with other provider organisations and in future link this dataset to the chemotherapy dataset and chemotherapy experience survey to help understand the relationship between workforce and patient outcomes and support workforce planning.

**National BME Cancer Voice**

6.23. The National BME Cancer Voice has now recruited 320 members. The first national conference was held in Birmingham in July 2012, where members shared their experiences of cancer and caring for loved ones with cancer. Many people attending the conference felt that BME Cancer Voice was much needed and long overdue. Many said this was the first time they had felt the NHS was listening to their experiences.

6.24. Over 500 people have now completed the first in-depth survey looking at the information experiences of BME cancer patients, and a report will be published shortly. To support BME patient voices being heard, 18 members have shared their experiences on video. These videos, which will be available shortly, will provide newly diagnosed patients, their families, and healthcare professionals with useful information and practical advice on how to improve experience of BME patients.

**End of Life Care**

6.25. The fourth annual report on implementation of the End of Life Care Strategy was published by the Department of Health in October 2012. The Strategy covers deaths for all conditions and in settings. It aims to enhance choice and in particular to enable people to be cared for and to die at home when this is their wish.

**Indicator – proportion of deaths in usual place of residence**

6.26. Progress is measured through a Key Performance Indicator on improving the proportion of deaths in someone’s usual place of residence (DiUPR) which has been adopted for Quality Innovation Productivity and Prevention (QIPP).

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51 [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)
Latest data, for the period Quarter 1 2011-12 to Quarter 4 2011-12 show continuing improvement quarter by quarter, both nationally and regionally. DiUPR now stands at 42.4%. Deaths in hospital are dropping: the latest quarter suggests that they now account for just over 50%.

First national VOICES of bereaved people

In July the DH published the results of the first ever national survey of bereaved people. This showed that care in the last three months of life was rated most highly where someone died in a hospice and least well when they died in hospital. Hospices scored 59% for “outstanding/excellent”, home 54%, care home 51% and hospital 33%. Cancer patients and people aged under 65 were most likely to receive outstanding/excellent care.

This first survey will provide the base line data for an Indicator in the NHS Outcomes Framework. The sample size allows for analysis to Primary Care Trust cluster level and shows significant variation between localities. The second survey, currently underway, should allow analysis to clinical commissioning group (CCG) level.

Electronic Palliative Care Coordination Systems (EPaCCS)

EPaCCS record patients’ key information on their needs and choices for end of life care, working to an ISB information standard. Outcomes data from the early adopters show that they enable people to die in their preferred place for care. EPaCCS were trialled in eight pilot sites and are now being put in place across the country.

Palliative Care Funding Review

The independent Palliative Care Funding Review reported in July 2011. One of its key conclusions was that “There is a stunning lack of good data surrounding costs for palliative care in England.” It recommended that a number of pilots be set up to collect data and refine its proposals due to the lack of good quality data currently available. The Government accepted this recommendation.

Ministers selected and announced the seven adult and one children’s pilot sites in March 2012. The pilots are all local partnerships. The adult sites are being led by:

- NHS North Yorkshire and York
- St Christopher's Hospice, London
6.32. The pilot for children’s services is a consortium being led by the following organisations:

- East of England Child Health and Wellbeing Team
- West Midlands Paediatric Palliative Care Network
- Great Ormond Street Hospital, London
- Northwest Children and Young Peoples Palliative Care Network.

6.33. They will collect the data that will provide the information we need to test the Palliative Care Funding Review’s recommendations. The Government has provided £1.8 million funding support for the pilots over two years to March 2014. Ministers have requested that the new funding system be in place by 2015, a year sooner than the review proposed.

Caring for our future - reforming care and support - Social Care White Paper

6.34. End of life care spans both health and social care. QIPP highlights this connection in its emphasis on providing good quality care where people want it, in the community, with the focus on productivity aiming to avoid unnecessary hospital stays. Both of these point to improving community-based services, including end of life care in care homes. This is reflected in the White Paper on social care, Caring for our future: reforming care and support, published by the DH in July, which says:

“There has also been strong support for the Review’s recommendation that once a patient reaches the end of life stage, and is put on the end of life locality register, all health and social care should be funded by the state and be free at the point of delivery. We think there is much merit in providing free health and social care in a fully integrated service at the end of life.”
6.35. The White Paper goes on to say that the Government will work with the Palliative Care Funding pilot sites to collect the vital data and information needed to assess this proposal, and its costs. A decision on including free social care at the end of life in the new funding system will be informed by the evaluation of the pilots, and an assessment of resource implications and overall affordability.

6.36. In recognition of the scale of the task in getting these issues right, the Government has doubled its investment in the pilot sites from £1.8 million to £3.6 million to ensure we have the information needed for implementation.

Priorities for the coming year

6.37. The priority for the coming year is for the NHS to make use of the data available about cancer patients’ experience and the views of bereaved relatives and, on the basis of that material, take action to improve patient experience for the future.
7. NHS Outcomes Framework
Domain 5: treating and caring for people in a safe environment and protecting them from avoidable harm

Introduction

7.1. Patient safety is a concern in all areas of healthcare but, given the frequency of contact for those with cancer, it can be a particular issue for cancer patients. Historically the main focus for national patient safety policy has been the reporting of and learning from patient safety incidents – both those within and outside cancer services. This has led to the development of a number of initiatives with impacts on cancer services. With the closure of the National Patient Safety Agency (NPSA) and the move of national patient safety policy and strategy to the NHS Commissioning Board (NHS CB), there is now an opportunity to examine in detail where the principles of patient safety can be used to deliver further improvements in cancer care.

Safety of chemotherapy

7.2. The National Reporting and Learning Service received reports of three deaths and a further 400 patient safety incidents concerning oral anti-cancer medicines between November 2003 and July 2007. Half of these reports concern the wrong dosage, frequency, quantity or duration of oral anti-cancer medicines. It is also likely that there are substantial numbers of unreported incidents.

7.3. The number of orally active agents available, particularly the targeted therapies, is likely to increase substantially in the near future. The term oral anti-cancer medicines includes those with direct anti-tumour activity and targeted therapies such as kinase inhibitors. It does not include hormonal or anti-hormonal therapy used to treat cancer.

7.4. Doctors, nurses, pharmacists and their staff must prescribe, dispense and administer oral anti-cancer medicines to the same standard as injected therapy and must be monitored in the same way. More information is
7.5. There have been high profile deaths in the past caused by intravenous chemotherapy being administered by the spinal (intrathecal) route particularly involving maladministered intravenous vincristine by the spinal (intrathecal) route. The elimination of harm from this type of incident was one of the four specific targets in the Department of Health report *An Organisation with a Memory* (2000). Since then significant work has been undertaken and, while there have been no further reports of intravenous vinca alkaloids being administered by the spinal route in the UK, additional deaths have occurred in other countries.

7.6. One of the identified ways to reduce the risk of this type of incident was to introduce a novel type of connector that is not compatible with the very widespread “Luer” type connectors. Consequently, the NPSA issued an alert in which all NHS healthcare organisations were asked to ensure that:

- from 1 April 2012 all spinal (intrathecal) bolus doses and lumbar puncture samples are performed using syringes, needles and other devices with connectors that cannot connect with intravenous Luer connectors (the “Part A” alert)
- from 1 April 2013 all epidural, spinal (intrathecal) and regional infusions and boluses are performed with devices that use safer connectors that cannot connect with intravenous Luer connectors or intravenous infusion spikes (Part B)

7.7. Similar guidance has also been issued on a European basis following fatalities from wrong route chemotherapy in Italy and France.

7.8. An External Reference Group on Safer Neuraxial Devices bringing together industry and clinicians has been helping drive forward the introduction of safer connectors in the NHS. This group continues to monitor the development of safer connectors and their uptake by the NHS and good progress is being made in ensuring the risks of wrong route chemotherapy are being designed out of the NHS.

7.9. By November 2012 55 NHS Trusts in England have indicated that they have adopted the use of safer devices for spinal, intrathecal and lumbar puncture use. Additional testing is being undertaken within the NHS, to be completed by December 2012, to provide information on the integrity of the new syringes and syringe caps to prevent microbial contamination. Many Trusts have indicated they wish to select one connector design for both spinal and
epidural procedures in 2013 and have placed the continued use of intravenous devices for neuraxial procedures on the Trust risk register.

7.10. Last year we reported that good progress had been made in implementing the National Chemotherapy Advisory Group (NCAG) 2009 report recommendation that all Trusts with emergency departments should establish an Acute Oncology Service (AOS). To support the recommendation, an AOS brochure was published on the National Cancer Action Team website providing advice and examples of good practice. The recommendation has been carried into peer review measures, with visits by peer review teams reporting that only 13 out of 28 Cancer Networks have assessed Trusts as meeting 60% of the measures. The visits also highlighted some immediate risks, with services citing lack of funding and varying levels of engagement as issues.

7.11. A small group has been established to work with the Colleges and address appropriate training and education requirements for AOS as a sub-set of oncology.

Never events

7.12. Wrong route chemotherapy has been designated a national “never event” since 2009. This means it is considered completely unacceptable for this type of error to occur and that the leaders of healthcare organisations are tasked with ensuring that the appropriate processes and safeguards are in place to prevent this type of error. Commissioners are expected to focus on the occurrence of never events and are able to withhold payment from organisations in which never events occur. Their occurrence should also be publically declared, serving as a further deterrent and incentive to prevent their occurrence.

7.13. There are a number of other “never event” categories that are relevant to cancer services. These include a series of surgical never events which are to be the focus of renewed activity to drive down occurrence. Further information on never events and their occurrence is available at: http://www.dh.gov.uk/health/2012/10/never-events/

Priorities for the coming year

7.14. The newly established patient safety team in the NHS CB has identified a number of priorities for delivery. These have clear implications for the safety of cancer services, including:
• **increasing our understanding** - how to routinely, accurately and affordably measure harm, and how to do so from the patient perspective

• **supporting the front line** - embedding a positive safety culture and an understanding of safety in all areas of healthcare

• **focus outside the acute setting** - bringing new focus on safety outside the acute setting, ensuring patients receive safe care wherever they are, especially given the ongoing shift in the way care is delivered from hospital to the community

• **high priority issues** - medicines safety is an area of particular concern, not just in cancer services but across the NHS, and communication of information during handover of care can also be a particularly dangerous time

• **harness learning from safety incidents** - unleashing the power of the National Reporting and Learning System, providing far easier access and promoting learning through opening the data up to those who can really extract value from it, and developing an enhanced and reactive reporting and learning system which actively encourages the frontline to report incidents and engage with improving patient safety.

7.15. The National Cancer Intelligence Network has plans to do further analyses of 30-day mortality post radical treatment. Information about outliers will help inform commissioners and providers about possible safety issues.
8. Delivering change

Introduction

8.1. There has been a range of work undertaken to support improvements in outcomes and productivity at a local level.

Support for commissioners and providers

8.2. As described earlier, a range of new intelligence has been provided to support commissioners and providers and further work is underway.

8.3. Building on the key messages for commissioners that were developed at the end of 2011-12, further work has been undertaken to support commissioners of cancer services. A major piece of work has been undertaken to support the development of service specifications for both specialist cancer services, which will be commissioned by the NHS Commissioning Board (NHS CB) as well as those cancer services that will be commissioned by clinical commissioning groups (CCGs). To date 15 specialist service specifications have been drafted as part of the work undertaken by the Specialised Cancer Clinical Reference group and three advisory service specifications for CCGs in breast cancer, colorectal cancer and lung cancer have been produced.

Holding organisations to account for delivery

8.4. We have previously described the indicators in the Public Health and NHS Outcomes Framework against which progress will be assessed. The NHS CB will decide on how it will hold CCGs to account for their performance and they are expected to publish details in due course. In the meantime the Health and Social Care Information Centre is working with the London School of Hygiene and Tropical Medicine and the Office of National Statistics to develop a methodology for measuring cancer survival rates at CCG population level, so that CCG performance can be assessed.

NICE Quality Standards

8.5. As well as the breast cancer quality standard published in October 2011, the National Institute for Health and Clinical Excellence (NICE) has now published Quality Standards for colorectal, lung cancer and ovarian cancer. The NICE prostate cancer quality standard is being developed as part of the review of the NICE prostate cancer clinical guideline. Quality standards for haematological malignancies, head and neck cancer, sarcoma, skin cancer
OSCC: Second Annual Report
(including melanoma), children and young people with cancer, metastatic spinal cord compression, referral for suspected cancer and bladder cancer are being developed.

Tariffs

8.6. Work has been continuing to promote better coding, recording and costing of chemotherapy and radiotherapy. The Department of Health (DH) is moving away from block contract funding arrangements for external beam radiotherapy and, following the mandate of a national currency in 2012-13 for the contracting of external beam radiotherapy, is introducing a mandated tariff for a minimum of 50% of contract values in 2013-14. The prices for 2013-14 are currently being sense checked.

8.7. We are continuing to publish mandatory tariffs for diagnostic imaging accessed directly (eg when requested by a GP). We are currently assessing proposals to publish tariffs for diagnostic imaging in outpatients separately from outpatient attendance tariffs.

8.8. Mirroring the approach applied to external beam radiotherapy, the mandate of the national currency for chemotherapy delivery was introduced in 2012-13, with national mandated tariff prices introduced for a minimum of 50% of contract values in 2013-14. Again, the prices for 2013-14 are currently being sense checked.

8.9. The National Cancer Action Team and DH are working on updating the national chemotherapy regimen for publication by NHS Connecting for Health in early 2013, when the new list will have in excess of 800 regimens on it including the updated paediatric regimens. We are now working to develop a longer-term strategy for the maintenance of the national regimen list.

Clinical networks

8.10. Both DH and the NHS CB have made it clear that there is a role for clinical networks, such as Cancer Networks, in the reformed NHS. The Networks are a place where clinicians from different sectors come together to improve the quality of care across integrated pathways. Cancer Networks are a clear example of how this way of working delivers better quality care and improves outcomes.

8.11. DH is continuing to fund the Cancer Networks in 2012-13. From April 2013, the funding of clinical networks will be a decision for the NHS CB. The NHS CB will also set levels of accountability.
In order to consider, the functions, structures and governance that will mostly effectively support commissioners to deliver improved quality and outcomes in the future, a review of clinical networks began in 2011. The review received input from over 800 stakeholders, including representatives from Cancer Networks.

The outcome of the review was published in a report by the NHS CB in July 2012. In the report, the NHS CB made its recommendations for the future of clinical networks in the new NHS. The NHS CB published *Strategic Clinical Networks: Single Operating Framework* on 12 November 2012.

For 2013-14, £42 million has been allocated by the NHS CB to support Strategic Clinical Networks and Clinical Senates of which it has been assumed that £10 million will count against the Board’s own running costs allocation.

It is proposed that this element of the total should be divided equally between 12 support teams as core funding, with the remaining £32 million to be allocated according to population size, taking into account rurality and inequalities. These support teams will cover defined geographical areas that could contain one or more Cancer Networks.

The 12 teams will be hosted by NHS CB Local Area Teams (LATs) and will be accountable to the Operations Directorate. We expect an arrangement that would see support teams employing their skills across different networks as needed, but one that would also involve designated subject experts, such as those with expertise in cancer commissioning.

The support teams will provide robust project and programme management expertise to help the delivery of quality improvement programmes. This will include providing expertise and advice on the implementation of best practice models and pathways of care, based on nationally agreed best practice and making full use of all the available quality standards and commissioning enablers.

**National support for service improvement**

NCAT and NHS Improvement have continued to provide important support for delivering improvements in cancer services and outcomes. For example, NHS Improvement has been working with a range of Trusts to help deliver

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52 *The Way Forward: Strategic Clinical Networks* (NHS Commissioning Board Authority, 31st July 2012)  
increased endoscopy capacity and reductions in the use of hospital bed
days. Work is underway to transfer relevant functions of NCAT and NHS
Improvement to the new improvement body in the NHS CB.

Research

8.19. The National Institute for Health Research (NIHR) Cancer Research Network (NCRN) has dramatically increased our ability to carry out clinical trials. The percentage of cancer patients in trials in England is now more than twice that of the United States and the UK now has the highest national per capita rate of cancer trial participation in the world. By 2011, more than 1 of every 5 newly diagnosed patients were taking part in cancer studies.

8.20. In partnership with Cancer Research UK, the NIHR funds 14 Experimental Cancer Medicine Centres across England. These help to ensure that patients will benefit from leading-edge treatment in world-class facilities, and that England remains at the forefront of international efforts to develop new treatments for all types of cancers.

8.21. In April 2012, NIHR launched an update to the UK Clinical Trials Gateway. This website significantly increases and improves the amount of information about clinical trials available to patients, clinicians and the public. Versions of the Gateway are also now available for the iPhone, iPad and Android devices.

8.22. The NIHR Cancer Biomedical Research Centre at The Royal Marsden Hospital/Institute of Cancer Research has been awarded £61.5 million funding between 2012 and 2017.

8.23. The NIHR is funding a whole range of cancer research across its many funding schemes. The focus is always the benefit that the research will bring to patients and the public. Research applications are subject to peer review and judged in open competition, with awards being made on the basis of the scientific quality of the proposals made.

8.24. DH works closely with its cancer research funding partners through the National Cancer Research Institute (NCRI). The NCRI is a strategic partnership of 22 government, charity and industry cancer research funders, together with patients. Through the NCRI we are able to take a more strategic approach to cancer research and make sure that major funders, the industry and patients can work in partnership.
Funding

8.25. As set out in *Improving Outcomes: A Strategy for Cancer* (ISOC), additional funding has been put into Primary Care Trust baselines to meet the costs of additional referrals associated with earlier diagnosis of symptomatic cancers, extensions to the bowel and breast cancer screening programmes and additional radiotherapy attendances. In addition, central funding has been provided for running *Be Clear on Cancer* campaigns, supporting GPs with diagnosis of possible cancer symptoms, introduction of the flexible sigmoidoscopy bowel screening programme and a range of other smaller activities such as the establishment of the new Diagnostics Imaging Dataset.

Cancer programme in the new structures

8.26. Over the last few months, a lot of work has been done to clarify where current functions of the DH cancer policy team, NCAT, NHS Improvement, NHS Cancer Screening Programmes and National Cancer Intelligence Network will sit in the new structures. This work is ongoing, but it is fully recognised that mechanisms will be needed to ensure appropriate governance and coordination of work.

8.27. The NHS CB will lead on annual reports on IOSC, with contributions from other bodies such as Public Health England and DH as appropriate.

8.28. The IOSC Implementation Advisory Group (IAG) will continue to advise all the bodies charged with improving outcomes for cancer patients. This will be through Professor Sir Mike Richards in his role as Director for reducing premature mortality (Domain 1) in the NHS CB. He will take responsibility for advising Ministers and others on the basis of the views expressed by the IAG. The secretariat for the IAG will also sit with Domain 1 of the NHS CB. The IAG will be chaired by Dr Harpal Kumar, Chief Executive of CRUK, and the membership of the group is being refreshed to reflect the new health and care system, for example by having representation from CCGs.

8.29. Existing advisory groups on specific cancers, such as the Breast Cancer Working Group and the Prostate Cancer Advisory Group, will continue to play an important role as forums for the full breadth of stakeholders to express and feed in their views. However, these groups are now likely to be led and managed by third sector partners to reflect an independence from the new formal bodies. These groups are likely to feed into the IOSC IAG.
8.30. The new structures provide an excellent opportunity for improvements in the commissioning and provision of cancer services, in order to deliver improved outcomes in line with the Outcomes Frameworks. The priority for the year ahead is for all concerned to work together to ensure that the new mechanisms and relationships are established to ensure that the opportunities are seized, with the patient as the central focus for all that we do.
Annex A: Diagnostic Imaging Dataset analysis

Count of chest X-rays referred via GP direct access and the percentage of GP direct access referrals compared to all referral types, for <75s

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<th>June</th>
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<td>GP direct</td>
<td>% of all</td>
<td>GP direct</td>
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<tr>
<td></td>
<td>access</td>
<td>referral</td>
<td>access</td>
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Count of non-obstetric ultrasounds referred via GP direct access and the percentage of GP direct access referrals compared to all referral types, for <75s

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<td>GP direct</td>
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Count of brain MRIs referred via GP direct access and the percentage of GP direct access referrals compared to all referral types, for <75s

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<td>2.0%</td>
<td>127</td>
<td>2.3%</td>
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<td>239</td>
<td>9.1%</td>
<td>261</td>
<td>10.7%</td>
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<tr>
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<td>3.0%</td>
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<td>2.8%</td>
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<tr>
<td>South West SHA</td>
<td>136</td>
<td>6.2%</td>
<td>145</td>
<td>5.7%</td>
<td>217</td>
<td>9.8%</td>
</tr>
</tbody>
</table>

To Note:
- These data are taken from the Diagnostic Imaging Dataset. The collection of these data is in its infancy and so labelled as provisional and experimental.
- These data exclude those categorised by their date of birth as aged 75 or over, however do contain those records where a date of birth was not recorded.
- The date of birth was recorded for 99.5%, 98.4% and 98.5% of records in April, May and June respectively.
- The England total does not equal the sum of the SHA totals. This is because the England total also includes activity from independent sector providers.
- Chest X-ray is defined as all records coded for the following procedures:
  - XR chest
- Non-obstetric ultrasound is defined as all records coded for the following procedures:
  - US abdomen
  - US abdomen and pelvis
  - US lower abdomen
  - US upper abdomen
  - US doppler renal both
  - US doppler renal left
  - US doppler renal right
  - US kidney both
  - US kidney left
  - US kidney right
  - US urinary bladder
- Brain MRI is defined as all records coded for the following procedures:
  - MRI head
  - MRI head with contrast
- Referral types are based on intended management at the time of the diagnostic test request, and categorised as:
  - Admitted Patient Care - Inpatient
  - Admitted Patient Care - Day case
  - Outpatient
  - GP Direct Access
  - Accident and Emergency Department
  - Other Health Care Provider
  - Other
Annex B: Routes to diagnosis for all cancers combined, breast cancer and kidney cancer

The following examples from *Routes to Diagnosis* show the proportion of cancers by age and route for all cancers combined and the proportion and corresponding 1-year relative survival by age and by route for breast and kidney cancer.

All cancers – proportion by route and age group

**C00-C97 excluding C44: All cancers (excluding NMSC): Percentage by Route and age group, 2006-2008, England**

Breast cancer – proportion by route and 12-month relative survival estimates by age group

**C50: Breast cancer: Percentage by Route and age group, 2006-2008, England**
C33-C34: Lung cancer: Percentage by Route and age group, 2006-2008, England

IOSC: Second Annual Report

Kidney and unspecific urinary cancers – proportion by route and 12-month relative survival estimates by age group

C64-C66, C68: Kidney and unspecific urinary organs:

[Graph showing percentage of patients by route and age group for cancer of the kidney and unspecified urinary organs, 2006-2008, England]

C64-C66, C68: Kidney and unspecific urinary organs: 12-month relative survival by diagnosis route and age groups

[Graph showing 12-month relative survival estimates by route and age for kidney and unspecified urinary organs, 2006-2008, England]
Annex C: Levels of ambition for cancer survival

Projection of survival and avoidable premature deaths among cancer patients who will be diagnosed in England during 2012-14 and 2014-16

The central ambition in Improving Outcomes: a Strategy for Cancer (IOSC)\(^1\) is to halve the number of “avoidable premature deaths” among cancer patients in England from 10,000 to 5,000 by 2015 - or, as expressed in IOSC, “to save 5,000 lives”. Avoidable premature deaths are the cancer-related deaths that occur among cancer patients within five years of diagnosis (premature) and that would not be expected to have occurred if survival in Britain matched the level of the best seen in Europe (avoidable).

The concept arises from a comparison of five-year relative survival from each cancer in Britain (England, Scotland and Wales) with the average or highest levels of survival seen in Europe\(^2\). This study suggested that about 11,400 avoidable premature deaths occur each year among cancer patients in Britain (or 10,000 in England alone). These estimates were derived from the EUROCARE-2, -3 and -4 studies, which covered patients diagnosed in the UK and 13 other European countries during 1985-89, 1990-94 and 1995-99, respectively\(^3\)\(^-\)\(^5\). Results from EUROCARE-5, covering patients diagnosed up to 2007, will not be available until 2013.

In the interim, we have used data from the International Cancer Benchmarking Partnership (ICBP) study\(^6\) to estimate the annual number of avoidable premature deaths from cancers of the large bowel (colorectum), lung and breast in England if the differences reported in the ICBP study in five-year relative survival for patients diagnosed during 2005-07 in England, in particular, and the average for Australia, Sweden and Canada (“AUSWECAN”) were to be halved by 2012-14, or by 2014-16. To do this, we first estimated how many cancer patients might be diagnosed each year in England in those periods, and the survival that those patients may be expected to experience if the “level of ambition” for avoidable deaths were to be achieved.

Estimating avoidable premature deaths from the ICBP data has the advantage that survival estimates for patients diagnosed up to 2007 are available, but it has disadvantages. First, the comparator populations in ICBP are Australia, Sweden and Canada, not the 13 European countries on which the IOSC target is based. Second,
ICBP survival estimates are only available for cancers of the bowel, lung and breast (cancer of the ovary was not considered here, because it contributes less than 5% of avoidable premature deaths in England with respect to Europe). Third, we have to base our estimate of the number of avoidable deaths within five years of diagnosis among patients who will in due course be diagnosed during 2012-14 or 2014-16 (and ultimately followed up for five years to 2021) on the survival that has actually been observed for patients diagnosed between 2000 and 2007, some 14-20 years earlier.

This has several implications. The EUROCARE survival estimates that underpin the IOSC target were cohort (longitudinal) estimates, in which most patients had been followed up for at least five years. The ICBP five-year survival estimates were based on patients diagnosed during 2000-07 who were still alive at some point during 2005-07 (“period” estimates). Period estimates are known to provide fairly good short-term predictions of survival\textsuperscript{7}, even though not all the patients included in the analyses will have been followed up for a full five years. Period estimates are nevertheless based on data from cancer patients who have been diagnosed in the past and who have been followed up to observe their survival. By contrast, projections into the future require assumptions about the likely patterns of survival among cancer patients who have not yet been diagnosed. Here, we needed to project recent trends in five-year relative survival (for patients diagnosed up to 2007) by up to 9 years, to 2016, both for England and for the comparator countries, then to apply these projected survival estimates to the number of cancer patients that we project to be diagnosed in England during those periods. This is more speculative than basing the calculation of avoidable deaths on the survival of cancer patients who have actually been observed; the assumptions involved cannot be tested. Ideally, also, incidence projections would have been derived from age-period-cohort models that can account for the impact of the year of birth (cohort) in the risk of being diagnosed with cancer at a given age in a given calendar period: these methods could not be deployed in the available time.

**Method**

Annual incidence rates in broad age bands were derived for each cancer in each of the years 2005-09 from the numbers of cases registered in England by five-year age group and sex, and the corresponding inter-censal population estimates (Office for National Statistics). Incidence rates for 2013 and 2015 were derived by linear projection of the incidence rates by age and sex. The numbers of persons who may expect to be diagnosed with cancer in 2013 and 2015 were then derived by applying
these projected incidence rates to the official population projections for that year (Government Actuary’s Department). Linear projection of incidence rates in broad age bands amounts to using a linear age-period (“drift”) model which, for some cancers, may be too simplistic.8

The estimates of observed, expected and relative survival for each cancer by age and sex, taken from the ICBP study, were also projected to 2012-14 and 2014-16, both for “AUSWECAN” and for England. The absolute annual percentage change (slope) in survival was taken as one-fifth of the difference between the values for 2005-07 and 2000-02 (five years). Projected values for 2012-14 are those for 2005-07 plus 7 times the absolute annual change (2005-07 to 2012-2014 is 7 years). Similarly, projected values for 2014-16 are those for 2005-07 plus 9 times the absolute annual change. Any more complex projection of survival would have required survival estimates for each calendar year of diagnosis. Projection of survival into the future also involves strong assumptions about changes (or lack of them) in patterns of access to diagnosis, in the efficacy of treatment, in the speed with which more effective new treatments that may be introduced in the near future become widely available, and in the overall effectiveness of health care systems. Making such projections for several countries involved an even wider degree of licence in these assumptions, which cannot be tested.

Avoidable deaths for 2012-14 and 2014-16 were then estimated in the same way as for 2005-07. However, instead of using the value predicted by the underlying trend for England, it was also assumed that relative survival in England had reached the “level of ambition”, which is mid-way between the projected value for AUSWECAN and the projected value for England.

Results

The projections suggest that survival for breast cancer in England would be expected to reach levels close to those in Australia, Sweden and Canada for women diagnosed in 2014-16 (Figure 1), given the caveats about this type of projection (see below). The survival projections for colorectal cancer do not suggest much change in the difference in survival. The projections for lung cancer survival suggest the difference may widen somewhat.
Projections of the avoidable premature deaths are shown in the table. These results incorporate the assumption that the projected differences in survival would be halved by 2014-2016, in other words, that England would “catch up” half of the current survival deficit. On that basis, the number of avoidable premature deaths from breast cancer would drop from about 1,660 to about 200 a year. Taking account of projected changes in incidence, this would represent a substantial reduction in the proportion of cancer-related deaths within five years of diagnosis that would be still considered avoidable, from 25% to 4%.

For lung cancer, the projections suggest little change in avoidable premature mortality, from about 6-8% of the overall excess mortality for patients diagnosed in 2005-07 to about 5-6% for patients diagnosed during 2014-16. Taking account of changes in incidence, this would be equivalent to a fall from about 2,100 to 1,700 avoidable premature deaths each year. The relatively small gain reflects both the low survival from lung cancer in both sexes and the fact that survival has barely been changing in England, whereas it has been increasing in the other 3 countries; thus, even if the ambition to halve the projected gap in survival were achieved, the absolute difference in survival would not change greatly (see Figure 3).

For colorectal cancer, the projections suggest that avoidable premature mortality could drop from 17-19% of cancer-related mortality to around 10-13% for patients diagnosed during 2014-16, equivalent to a fall from 2,600 to 1,700 avoidable premature deaths each year.

**Caveats**

The scientific consultants from the London School of Hygiene and Tropical Medicine draw attention to the following caveats that apply to the interpretation of these data and graphics.

Relative survival estimates for Australia, Sweden and Canada (“AUSWECAN”), and for England, were obtained by assuming a linear trend of five-year survival from the values observed for patients diagnosed during 2000-02 and 2005-07, and projecting this trend for the 7 years to 2012-14 (and 9 years to 2014-16). More reliable estimates would have required using “scenario” models to take into account the changes in survival due to the introduction of (or wider access to) new staging procedures, screening programmes and treatment. It would also have required more
In order to project the annual number of avoidable premature deaths among cancer patients diagnosed in England in 2012-14 if the level of ambition were to be achieved, it was also necessary to estimate:

- The expected five-year survival in England among patients diagnosed in England during 2012-14. A simple linear trend was assumed, with the slope observed between 2000-02 and 2005-07, again for 7 or 9 years.
- The projected annual number of new diagnoses in England during 2012-14. To obtain this number, the most recent incidence rates (for 2005-09) were projected and applied to the official population projections for 2013 or 2015 in England, by age and sex. Again due to time constraints, a simple linear trend was assumed for the 7 years to 2012-14 or 9 years to 2014-16.

References

2. Abdel-Rahman MA, Stockton DL, Rachet B, Hakulinen T, Coleman MP. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? Br J Cancer 2009; 101 (Suppl. 2): 115-24
Notes to Figures 1-3

For patients diagnosed during 1995-99, 2000-02 and 2005-07, data are taken from the ICBP study: “AUSWECAN” - mean of the age-standardised 5-year relative survival estimates for Australia, Sweden and Canada; England – age-standardised 5-year relative survival in England. The solid lines indicate the trend between the estimates obtained from observed data (ICBP study).

For patients diagnosed during 2012-14 and 2014-16, the survival estimates derived from the ICBP study for “AUSWECAN” and England were projected on the basis of the most recent slope between the estimates for 2000-02 and 2005-07. The dashed lines indicate the trend between the estimates obtained from projected data.

For England, an alternative projection was considered, to represent the idea of “halving the gap” (orange dashed line). This projection represents the mid-point between projected survival estimates for “AUSWECAN” and England for patients diagnosed during 2012-14 and 2014-16.

Figure 1

Five-year age-standardised relative survival (RS, %) for women diagnosed with breast cancer aged 15-99 years in England and in Australia, Sweden and Canada (“AUSWECAN”: observed for women diagnosed during 1995-2007, projected for 2012-16 (see notes to Figures 1-3)
Figure 2

Five-year age-standardised relative survival (RS, %) for patients diagnosed with colorectal cancer aged 15-99 years in England and in Australia, Sweden and Canada ("AUSWECAN"): observed for patients diagnosed during 1995-2007, projected for 2012-16 (see notes to Figures 1-3)

Figure 3

Five-year age-standardised relative survival (RS, %) for patients diagnosed with lung cancer aged 15-99 years in England and in Australia, Sweden and Canada ("AUSWECAN"): observed for patients diagnosed during 1995-2007, projected for 2012-16 (see notes to Figures 1-3)
Annual number of observed, excess and avoidable deaths within five years of diagnosis, England, 2005-07, and projected for 2012-2014 and 2014-2016 under the assumption that the "level of ambition" for survival has been attained: selected cancers, by sex and age group at diagnosis

<table>
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<tr>
<th>Cancer Type</th>
<th>2005-07 (period survival estimates)</th>
<th>2012-14 (projected survival estimates)</th>
<th>2014-16 (projected survival estimates)</th>
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<tr>
<td></td>
<td>Observed</td>
<td>Excess</td>
<td>% of excess</td>
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<td></td>
<td></td>
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<tr>
<td>15-44</td>
<td>168</td>
<td>167</td>
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<td>55-64</td>
<td>1,496</td>
<td>1,378</td>
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<td>65-74</td>
<td>2,891</td>
<td>2,425</td>
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<td>75-99</td>
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<td>Women</td>
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<tr>
<td>15-44</td>
<td>151</td>
<td>151</td>
<td>17.9</td>
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<td>45-54</td>
<td>850</td>
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<td>55-64</td>
<td>3,231</td>
<td>3,210</td>
<td>7.6</td>
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<td>65-74</td>
<td>5,599</td>
<td>5,527</td>
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<tr>
<td>75-99</td>
<td>7,860</td>
<td>7,747</td>
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<td>17,497</td>
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<td>Men</td>
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<tr>
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<tr>
<td>45-54</td>
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<td>847</td>
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<tr>
<td>75-99</td>
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<td>7,747</td>
<td>4.4</td>
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<tr>
<td>Total</td>
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<td>17,497</td>
<td>16.6</td>
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<tr>
<td>Women</td>
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<td></td>
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<tr>
<td>15-44</td>
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<td>151</td>
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<td>7,860</td>
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<td>4.4</td>
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<tr>
<td>Total</td>
<td>17,706</td>
<td>17,497</td>
<td>16.6</td>
</tr>
</tbody>
</table>

Observed deaths: annual average number of deaths (all causes) in England within five years of diagnosis among cancer patients who were included in the International Cancer Benchmarking Partnership (ICBP) survival analyses (1).

Excess deaths: difference between observed and expected number of deaths (all causes) in England, where the expected number is derived from life tables of background mortality rates by single year of age, sex and single calendar year in the relevant period.

Avoidable deaths in 2005-07: sub-set of the excess deaths that would not be expected to arise if five-year relative survival by age and sex in England were the same as the unweighted average value for Australia, Sweden and Canada (AUSWECAN). Presented as a number, and as a percentage of the total number of excess deaths in England.
Avoidable deaths for 2012-14 and 2014-16: estimated in the same way as for 2005-07. However, instead of using the value predicted by the underlying trend for England, it was assumed that relative survival in England had reached the “level of ambition”, which is mid-way between the projected value for AUSWECAN and the projected value for England.

Survival: the underlying relative survival estimates for patients diagnosed in 2005-07 were derived with the period approach (1).


2 Abdel-Rahman et al. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? British Journal of Cancer 2009; 101 (Suppl. 2): 115-124.
Annex D: High level cancer equality metrics

After consultation and discussion with the National Cancer Intelligence Network (NCIN) and the National Cancer Equality Initiative Implementation Advisory Group (NCEI IAG), the following high level metrics have been agreed.

It is suggested that, unless stated otherwise, collection and analysis should be undertaken annually for “all cancers combined (excluding non-melanoma skin cancer)” and for specified cancer type groupings.

1. Cancer incidence (for latest year available) and incidence rates

   1.1. Total number of new cases in England for all cancers combined and for the four most common cancers*

   1.2. Total number of new cases by age (0-14, 15-24, 25-64, 65-74, 75-84, 85+)\(^{54}\)

   1.3. Age-standardised rate ratios by gender (male, female) for non-gender specific cancers

   1.4. Trends in number of new cases (over previous 10 years)

   1.5. Total number of new cases and age standardised rate ratios by deprivation for all cancers combined and for the four most common cancers*

   1.6. Total number of new cases by major ethnic group (for all cancers combined, breast, colorectal, lung, prostate and other)

     Data processed by: NCIN

2. Number of cancer deaths and mortality rates (for latest year available)

   2.1. Total number of deaths in England for all cancers combined and for the four most common cancers*

   2.2. Total number of deaths by age bands (0-14, 15-24, 25-64, 65-74, 75-84, 85+)

   2.3. Age-standardised rate ratios by gender (male, female) for non-gender specific cancers

   2.4. Trends in number of deaths (over previous 10 years)

   2.5. Total number of deaths and age standardised rate ratios by deprivation

   2.6. Total number of deaths by major ethnic group and unrecorded / unknown ethnicity (for all cancers combined, breast, colorectal, lung, prostate and other)

     Data processed by: NCIN

\(^{54}\) Use of 0-14 here originates from census data. The age bands used in CYP cancer settings (0-15, 16-24) are based on population data and so beyond our remit to amend.

* Breast cancer, lung cancer, colorectal cancer and prostate cancer
3. **One year relative survival from cancer** (for breast, colorectal, lung and prostate cancers)

   3.1. Trends in one year relative survival
   3.2. One year relative survival by age (<65, 65-74, 75+)
   3.3. One year relative survival by gender (male, female) non-gender specific cancers
   3.4. One year relative survival by deprivation
   3.5. One year relative survival by ethnicity (White, Non White, Not Recorded)\(^{55}\)

   Data processed by: NCIN

4. **Ethnicity coding compliance**

   4.1. The % of cancer patients who have an ethnicity record\(^{56}\)
   4.2. The % of all in-patients and of all out-patients who have an ethnicity code\(^{57}\)

   Data processed by: NCIN

5. **Cancer screening programme**

   5.1. The % screening coverage for cervical screening by deprivation and age
   5.2. The % screening coverage for breast screening by deprivation and age
   5.3. The % screening uptake\(^{58}\) for bowel screening by deprivation, age and gender

   Data processed by: NHSCSP

6. **Routes to diagnosis (for all cancers combined and for the four most common cancers\(^*\))**

   6.1. Proportion of Emergency Presentations by age (0-14, 15-24, 25-64, 65-74, 75-84, 85+)
   6.2. Proportion of Emergency Presentations by gender (male, female) for non-gender specific cancers
   6.3. Proportion of Emergency Presentations by deprivation
   6.4. Proportion of Emergency Presentations by ethnicity (White, Non White, Not Recorded)

   Data processed by: NCIN

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\(^{55}\) Intention to produce this in 2013/ 2014 onwards.

\(^{56}\) Initially look at 2002 – 2009, then every year.

\(^{57}\) NCIN to liaise with Information Centre re the availability of HES data for patients rather than by episode.

\(^{58}\) Coverage is not currently calculated for bowel cancer but will be later in 2012.

\(^*\) Breast cancer, lung cancer, colorectal cancer and prostate cancer
7. **Patient experience**
   7.1. Compare % of male patients reporting “worse experience” versus % of female patients reporting “worse experience”
   
   7.2. Compare across and between all age groups, looking at younger patients (aged 16-25) and older patients (75+), compared to those aged 26-74 reporting “worse experience”.
   
   7.3. The % of patients reporting “worse experience” by deprivation
   
   7.4. Compare % of non-white patients reporting “worse experience” versus % white patients versus non-recorded
   
   7.5. Compare % of non-heterosexual patients reporting “worse experience” versus % in heterosexual patients
   
   7.6. Compare % of patients with a long-term condition reporting “worse experience” versus % in patients without a long-term condition

Data processed by: NHS CB

8. **Radical treatment**
   8.1. Surgery (and/or radiotherapy and/or chemotherapy) rates by age, gender, deprivation and ethnicity

Data processed by: NCIN

9. **Stage at diagnosis**
   9.1. The % of staging data recorded at diagnosis
   
   9.2. Stage at diagnosis by age, gender, deprivation and ethnicity

Data processed by: NCIN

10. **Patient reported outcome measures (PROMs)**
    10.1. By age (16-49, 50-64, 65-74, and 75+), gender, deprivation and self-reported ethnicity

Data processed by: NHS CB

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59 From 2013-14 onwards. Age bands will begin at 25, as need at least a 5 year cohort of data to look at under 25s due to low numbers.

60 When national staging data has reached required level of completeness

61 From 2013-14 onwards
## Annex E: NCIN publications 2012

<table>
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<th>Publication Type</th>
<th>Title</th>
<th>Publication Date</th>
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<tr>
<td>Data Briefing</td>
<td>A Network’s Experience in Improving 1-Year Survival Rates in Lung Cancer</td>
<td>March</td>
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<tr>
<td>Report</td>
<td>Recurrent and Metastatic Breast Cancer Data Collection Project Pilot Report</td>
<td>March</td>
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<tr>
<td>Data Briefing</td>
<td>The Characteristics of Individuals with Colorectal Cancer who die Rapidly from their Disease</td>
<td>March</td>
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<td>Data Briefing</td>
<td>Understanding outcomes in leukaemia: why grouping difference cancer is misleading</td>
<td>May</td>
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<tr>
<td>Data Briefing</td>
<td>HPV related head &amp; neck cancers – time trends and age specific trends</td>
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<tr>
<td>Data Briefing</td>
<td>Co-morbidities of bone cancer patients</td>
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<tr>
<td>Data Briefing</td>
<td>Malignant Tumours of the vertebral column, sacrum, coccyx and base of skull, estimating annual incidence in England</td>
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<tr>
<td>Data Briefing</td>
<td>Incidence of sarcomas of the facial skeleton</td>
<td>May</td>
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<tr>
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Improving Outcomes: A Strategy for Cancer

5-year relative survival estimates

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South Central Strategic Health Authority

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South West Strategic Health Authority

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England

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Source: UKCIS, accessed November 2012

Tables contain 1-yr relative survival estimates for patients diagnosed in 2005-2009 followed up to 2010 and 5-yr relative survival estimates for patients diagnosed 2001-2005 followed up to 2010 for cancers of the breast (female only) ICD10 C50, colorectal ICD10 C18-C20 and lung ICD10 C33-C34. Relative survival estimates shown here are not age-standardised.

Relative survival provides an estimate of the percentage of patients still alive after the specified years from their diagnosis, whilst taking into account the background mortality in the general population (e.g. the percentage of patients that would be expected to have died from other causes during that period if they did not have cancer). It is therefore an estimate of the proportion of patients who survive their cancer for the specified time period.