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Improving Outcomes: A Strategy for Cancer

Third Annual Report

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Improving Outcomes: A Strategy for Cancer

Third Annual Report

Prepared by

Department of Health, Public Health England and NHS England (including NHS Improving Quality)

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Foreword

When *Improving Outcomes: a Strategy for Cancer* (IOSC) was published in January 2011, the Government committed to produce annual reports on progress on implementing the Strategy during transition and beyond. Professor Sir Mike Richards, as National Clinical Director for Cancer, submitted the first two annual reports, but has since moved on to become the first Chief Inspector of Hospitals. With the implementation of the new health and care structures from 1 April 2013, we are delighted to publish a joint Department of Health (DH), Public Health England (PHE), and NHS England third annual report.

The main focus of the IOSC was around improving cancer survival through earlier diagnosis of cancer and improved access to the best possible treatment. We are therefore pleased to be able to report on:

- Significant developments in cancer screening - particularly on the first phase of introducing Bowel Scope Screening (BSS)
- Activity to promote earlier diagnosis of symptomatic cancers, through the *Be Clear on Cancer* campaigns and the associated work with primary and secondary care
- Progress in ensuring better access for all to the best possible treatment, for example through improved access to Intensity Modulated Radiotherapy (IMRT)
- Significant developments in the collection and reporting of new datasets and the analysis of information, to drive improvements and to inform patients.

It is too early to be able to assess progress against the ambition to save an additional 5,000 lives per year by 2014/15, to halve the gap between the survival estimates in England and those in the best countries in Europe. However, we do know that:

- Cancer survival estimates and mortality rates continue to improve
- We are developing proxy measures to assess progress in a more timely manner, particularly in terms of the proportion of cancers diagnosed at stages one and two
- The NHS and Public Health (PH) Outcomes Framework indicators and the Clinical Commissioning Group Outcomes Indicator Set are starting to enable us to assess progress, at national and local level.

There is, as ever, much more to be done to maximise the scope to save lives (including from the rarer cancers) through preventing cancers, screening, early diagnosis of symptomatic cancers, improved access to treatment and better care for cancer survivors. Work continues in all these areas and the following will be priorities for next year:

- To continue to tackle the “lifestyle” factors, particularly smoking, which are responsible for over a third of cancers
- To improve uptake of screening amongst disadvantaged groups
- To continue to build on the *Be Clear on Cancer* campaigns and the growing evidence of their effectiveness
- To ensure there is sufficient endoscopy capacity to meet the needs of the bowel screening programme and the needs of symptomatic patients

- To continue to tackle variations in access to treatment, for example to provide comparative data on radiotherapy and chemotherapy to enable those with low levels to consider whether action is needed
- To keep a focus on the treatment older patients receive.

Of course, improving outcomes is not just about improving survival and mortality, it is about improving all outcomes. The report therefore also covers progress across all the relevant domains of the NHS and PH Outcomes Frameworks, including patient experience, support for cancer survivors and end of life care. Again, while there is progress to report, more needs to be done in the year ahead, for example locally by trusts with poor scores in this year's patient experience survey striving to do better and nationally by sharing the best practice of those trusts with higher scores.

Finally, there continues to be a need to tackle inequalities in access and outcomes. The Strategy made clear that the ambition to save an additional 5,000 lives every year by 2014/15 could not be met without narrowing the equalities gap. We report on good progress on targeted interventions to certain groups in the *Be Clear on Cancer* campaigns, and efforts to understand and tackle lower treatment rates in older patients. However, there is still much to do to narrow the equalities gap, particularly around patient experience, where some groups continue to report a worse experience.



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1. Introduction

Introduction

1.1. We have structured the report so that:

- We provide initially some brief background information about incidence, mortality, survival and spend
- Chapter 2 sets out an assessment of progress in relation to the new structures and systems and summarises the plans to improve cancer outcomes
- Chapter 3 describes progress in the collection and use of data, as a means of supporting improvement in services and outcomes
- The subsequent three chapters go through the patient pathway, focusing on prevention and early diagnosis, treatment, patient experience and survivorship – in terms of plans for improvements as set out in *Improving Outcomes: a Strategy for Cancer*.

Incidence, mortality and survival

Incidence trends

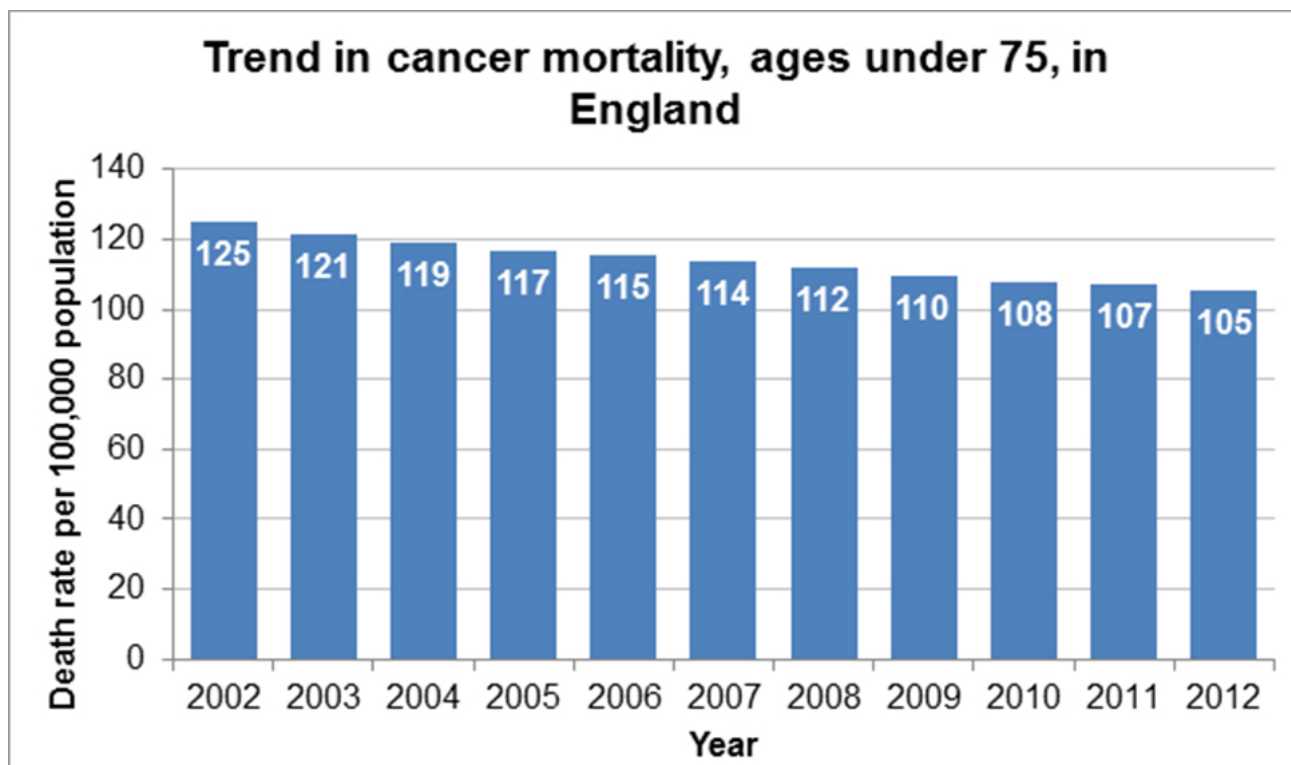
- 1.2. The 274,000 new cases of cancer registered in England in 2011 (139,000 in males and 135,000 in females) equate to an age-standardised rate of around 423 and 372 per 100,000 population respectively.¹ The number of registrations of new cases has increased by around 500 for males and 1,100 for females when compared to 2010. The four cancer types of breast, lung, colorectal and prostate continue to account for over half of newly diagnosed cases of cancer in England each year.
- 1.3. Between 1980-82 and 2009-11, the age-standardised incidence rate in England for all cancers combined increased by 16% in males and 32% in females. In recent years, the increase in cancer rates has been less marked than in earlier years, in particular for females. Between 2002-04 and 2009-11, the age-standardised incidence rates in England increased by 4% in males and 6% in females.
- 1.4. 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 2002-04 and 2009-11 age-standardised cancer incidence rates in those aged 75+ were relatively stable in males, and increased by 8% 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 9% in females.

¹ The figures presented for numbers and rates of 'all cancers' refer to all malignant neoplasms *ICD-10 C00-C97), excluding non-melanoma skin cancer (NMSC, ICD 10 C44). NMSC is very common, but as the available figures are known to be under-estimates and unreliable for comparison purpose, they have been excluded from the figures for 'all cancers'. Source: ONS.

Mortality trends

- 1.5. ONS mortality statistics show that cancers were the broad disease group which had the largest percentage of deaths registered in 2012, accounting for 29% of all deaths. In 2012, there were around 133,000 deaths at all ages in England where the underlying cause was cancer, 70,000 in males and 63,000 in females. Changes in mortality rates reflect changes in both incidence and survival. Cancer mortality rates (ages under 75) in England decreased over the last decade. The age-standardised cancer mortality rate (ages under 75) was 105.3 deaths per 100,000 population in 2012, a decrease of 16% since 2002.
- 1.6. Cancer mortality rates (ages under 75) have decreased in both more and less deprived areas, but there remains a social gradient in cancer mortality, with more deprived areas experiencing higher mortality rates than less deprived areas. In 2010 the cancer mortality rate (ages under 75) for the most deprived fifth of neighbourhoods in England was over one and a half times the rate in the least deprived fifth of neighbourhoods.

Figure 1.1 Trend in cancer mortality, ages under 75, in England



1) Based on deaths with underlying cause codes ICD10 C00-C97. Changes to the coding of cause of death were introduced for 2011 death registrations. The impact of the coding change on deaths assigned an underlying cause of cancer is very small (analysis of 2009 deaths indicated that deaths assigned to cancer increased by 0.5% as a result of the coding changes)

2) Rates are directly age-standardised to the 1976 European Standard Population

3) Rates for 2002 to 2010 are based on population estimates revised to take account of the 2011 Census

Source: Health and Social Care Information Centre, Compendium of Population Indicators

Survival

- 1.7. Five-year survival estimates for patients diagnosed with 21 common cancers have generally improved slightly or stayed the same during 2007-2011 compared to 2006-2010².
- 1.8. Five-year survival in 2007-2011 was over 80% for cancers of the breast (women), prostate, testis, Hodgkin lymphoma and melanoma of skin, but less than 21% in cancers of the brain, lung, oesophagus, pancreas and stomach in both sexes. Survival from pancreatic cancer remains the lowest in both sexes (4.7% for men, 5.4% for women).
- 1.9. Women have higher survival estimates for 12 out of the 15 cancers that are common to both men and women. The exceptions are bladder cancer, leukaemia, and myeloma. Net survival is often considerably lower among the elderly, even after adjusting for death from other causes.

Spend on cancer

- 1.10. Expenditure on cancer has increased from £3.19 billion in 2003/4 to £5.50 billion in 2011/12.³ This increase is broadly in line with the overall increase in NHS expenditure. The share of total expenditure (excluding Other Miscellaneous⁴) was 6.5% in 2004/5⁵ and 6.6% in 2011/12. This share of total expenditure peaked in 2009/10 at 6.8%.
- 1.11. A range of resources are available, such as the Spend and Outcomes Tool (SPOT)⁶ and the CCG Commissioning for Value packs⁷, that allow commissioners to explore the relationship between spend, activity and health outcomes in more detail in order to inform planning and prioritisation decisions.
- 1.12. There is large variation in expenditure levels between commissioners. The highest spending primary care organisation spends more than twice as much per person than the lowest spending organisation. It is unclear how much this variation can be explained by variation in the incidence and prevalence of patients with cancer and other factors.

² Source: ONS. <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/index.html>

³ Programme Budgeting aggregate Primary Care Trust expenditure. In order to improve data quality changes are made to the collection each year so caution should be used when comparing spend between years.

⁴ Some services cannot be attributed to programme categories, for example where information on the patients treated is not available (e.g. some Community Care services) or where the condition is unknown at the time of treatment (e.g. Diagnostic Imaging). This element of expenditure has changed over time so excluding this provides a more meaningful comparison between years.

⁵ The 'Other Miscellaneous' subcategory did not exist in 2003/4.

⁶ <http://www.yhpho.org.uk/default.aspx?RID=49488>

⁷ <http://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

2. Impact of new structures and arrangements on services and outcomes

Introduction

- 2.1. This chapter sets out how the new structures are working to improve cancer services and outcomes. In particular, it reports on the progress in improving cancer outcomes, as measured by the Outcomes Frameworks, and the work that NHS England and Public Health England (PHE) are proposing to take forward to deliver improved outcomes.

Update on Outcomes Frameworks

NHS Outcomes Framework

- 2.2. The NHS Outcomes Framework (NHS OF) encourages improvements in quality of care through a focus on improving health outcomes for all. The NHS OF provides a national level overview of NHS performance, wherever possible in an international context. It supports the Secretary of State in holding NHS England to account for improving outcomes for all and acts as a catalyst through the NHS by encouraging a change in culture and behaviour, including a stronger focus on tackling health inequalities.
- 2.3. 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.
- 2.4. Data to show progress in relation to the indicators were published in March 2013. The data can be found at: <https://indicators.ic.nhs.uk/webview/>. Those particularly targeted on cancer are the survival and mortality indicators within Domain 1 (the 2012 data for the cancer under 75 mortality indicator was added on 5 December 2013). All show improvements in the latest year for which data are available. The Health & Social Care Information Centre (HSCIC) indicator portal provides data on the indicators both at national and local level, enabling comparisons between different areas of the country, highlighting variations.
- 2.5. Since publication of the first NHS OF, work on developing indicators has continued. The Framework for 2013/14 included new indicators relating to cancer survival. We expect data for these indicators to be published by ONS on 10th December 2013 by Clinical Commissioning Group (CCG) and NHS England Area Team, and available on the HSCIC indicator portal in March 2014, including:

- 1.4.i One-year survival for all cancers
 - 1.4.ii Five-year survival for all cancers
 - 1.4.iii One-year survival for breast, lung and bowel cancer together; and
 - 1.4.iv Five-year survival for breast, lung and bowel cancer together.
- 2.6. These indicators are being developed by the London School of Hygiene and Tropical Medicine in collaboration with ONS and are composite indicators building on the work previously published on cancer survival rates for individual primary care trusts.⁸
- 2.7. Despite the change, we will still be able to monitor survival for breast, lung and bowel cancers individually and these will continue to be reported by ONS, subject to the outcome of the ONS consultation on statistical products. Updated data for the previous indicators (2007 to 2011 with 2012 as follow up) were published by ONS in October of 2013⁹, and the plan is to update the indicator data on the HSCIC portal in February 2014.
- 2.8. Finally, it is also expected that the data for indicator 1.6.iii Five-year survival for all cancers in children will be published by ONS on 10th December 2013, and available on the HSCIC indicator portal in March 2014. This indicator relates to children under 15 years and is a development of the original cancer survival indicators, which do not cover children under the age of 15 years, in recognition that cancer contributes to a significant proportion of childhood deaths.

Public Health Outcomes Framework

- 2.9. The Public Health Outcomes Framework (PHOF) *Healthy lives, healthy people: Improving outcomes and supporting transparency*, originally published in January 2012, sets out a vision for public health, desired outcomes and indicators to aid understanding of how well public health is being improved and protected.
- 2.10. The Framework concentrates on two high-level outcomes that we want to achieve across the public health system. These are: 1) Increased healthy life expectancy and 2) Reduced differences in life expectancy and healthy life expectancy between communities. It consists of 66 supporting public health indicators, grouped into four domains:
- Improving the wider determinants of health
 - Health improvement
 - Health protection
 - Healthcare public health and preventing premature mortality.

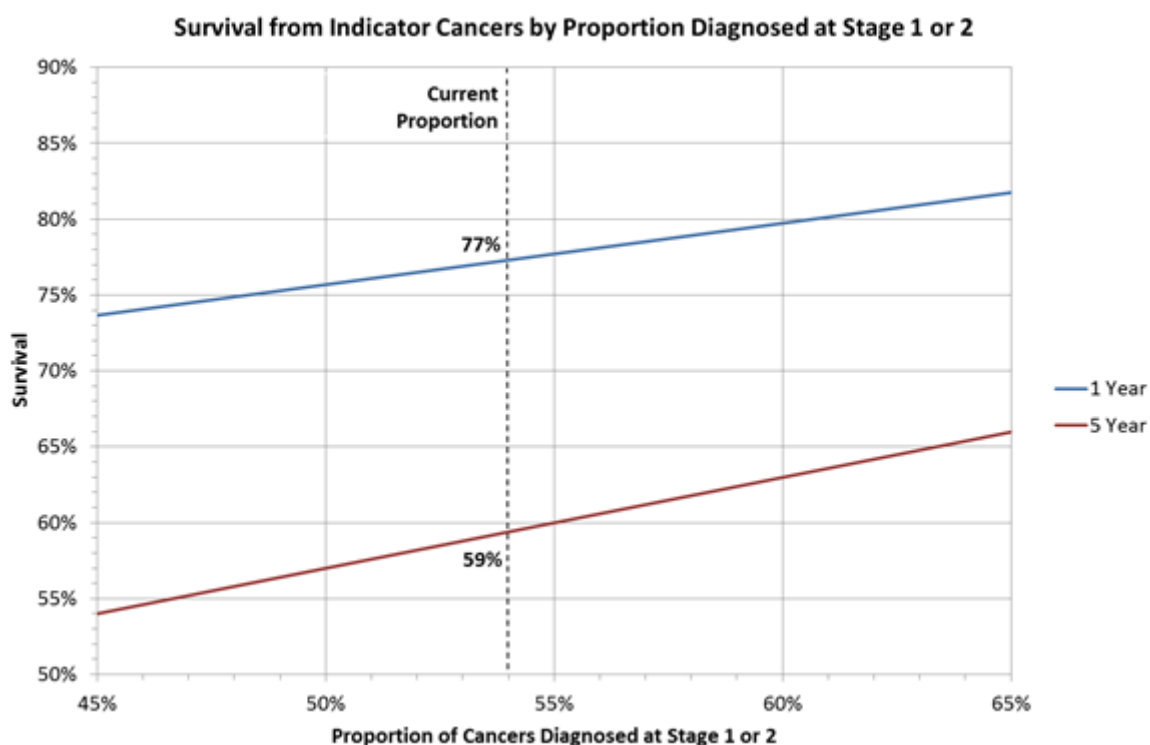
⁸ <http://www.ons.gov.uk/ons/rel/cancer-unit/combined-cancer-survival-by-primary-care-trusts/patients-diagnosed-1996-2010--followed-up-to-2011/index.html>

⁹ <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/index.html>

- 2.11. These indicators cover the full spectrum of what we understand public health to be, and what we can realistically measure at the moment. Where possible, each domain includes indicators across each stage of the life course, responding to the recommendations made by Sir Michael Marmot and Frank Field MP to focus on health inequalities.
- 2.12. These outcomes are intended to hold the whole public health system to account and can be improved only through partnership working between local government, Public Health England (PHE), NHS England, Department of Health and other government departments. These outcomes also enable each local authority to benchmark themselves against their own past performance, the national average and other local authorities.
- 2.13. Data for each PHOF indicator is published annually on the PHE website: www.phoutcomes.info/. Data updates are published on a quarterly basis (February, May, August, November) depending on the data cycle for each individual indicator.
- 2.14. The PHOF and NHS OF share the “under 75 mortality rate from cancer” indicator, recognising the critical contributions that both the NHS and the public health services can make to reducing “preventable mortality”. In having a shared indicator, with joint accountability for delivery, PHE and NHS England 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.
- 2.15. The latest publication of the PHOF indicator data shows a slight reduction in coverage for cervical screening. The trend downwards over recent years is of concern. More also needs to be done to improve uptake and coverage of bowel cancer screening (the data for this indicator will be added to the PHOF shortly), and to promote informed choice on breast screening in more disadvantaged groups. There is more information about screening in chapter 4 but, on the back of these concerns, uptake of screening will be a priority for the coming year.
- 2.16. The PHOF contains an indicator on the proportion of patients diagnosed with cancer at stage 1 and 2. All England data for this indicator are expected to be published in early 2014 based on 2012 data. However, as some parts of England already have staging data available for 2011, it is possible to report on preliminary baseline calculations. This indicator does not, of course, consider the impact of improved treatment, but it does serve as a useful proxy indicator for survival improvements.
- 2.17. In the East of England in 2011, the cancer registry collected staging data on 20,564 out of the 22,548 cases for cancer types covered by the indicator (91%). Of these, 12,074 (59%) were stage 1 or 2.
- 2.18. There were large differences between cancer sites, and between different groups in the community. Older patients were less likely to be diagnosed at an early stage than younger patients, and men were more likely to be diagnosed at a later stage than women. The type of cancer people are diagnosed with played an important part in these differences.

2.19. Using these East of England baseline data, we have modelled how many lives could be saved if there was an increase in the proportion of cancers diagnosed at stages 1 and 2. There are many assumptions made in doing this modelling, but it is interesting to note that for every increase of 1% in the proportion of cancers diagnosed at stages 1 or 2, an additional 800 patients are alive one year after diagnosis and an additional 1200 patients are alive 5 years after diagnosis. Figure 2.1 sets out, on the basis of this modelling, what impact increases in proportions of cancers diagnosed at stages 1 and 2 could have on cancer survival.

Figure 2.1 Survival for all cancers by proportion of cancers diagnosed at Stage 1 or 2¹⁰



Clinical Commissioning Group Outcomes Indicator Set

2.20. NHS England, supported by the National Institute for Health and Care Excellence (NICE), has developed a CCG Outcomes Indicator Set to provide clear, comparative information for CCGs, Health and Wellbeing Boards and local authorities about the quality of health services and associated health outcomes. All of the CCG outcomes indicators have been chosen on the basis that they contribute to the overarching aims of the five domains in the NHS Outcomes Framework. The Indicator Set is intended as a benchmarking tool for CCGs to drive local improvement and set priorities. The cancer

¹⁰ Survival rates were calculated for east of England residents diagnosed with cancer of the breast, prostate, colon, rectum, lung, bladder, kidney, ovary, uterus or non-Hodgkin's lymphoma or malignant melanoma of the skin. One year survival and incidence were calculated for patients diagnosed between 2006 and 2010 and five year survival for those diagnosed between 2001 and 2005. The current proportion of cancers diagnosed at stage 1 or 2 of 54% was calculated for east of England residents diagnosed in 2011. Survival rates from all ten cancers were calculated by weighting individual survival rates by incidence. Survival rates by proportion were calculated assuming the case mix by stage remained constant as proportion changed and that all cancers changed by the same proportion. Due to the low number of patients surviving to five years and the lack of data for patients in the East of England in the relevant time period Lung cancer was excluded from the five year survival calculations.

indicators in the CCG Outcomes Indicator Set 2013/14, which all match England level indicators in the NHS Outcomes Framework, are: under 75 mortality from cancer; one and five year survival from cancer; and one and five year survival from breast, lung and colorectal cancers combined. Further consideration is being given to other relevant indicators.

NHS England and the Mandate

- 2.21. In the Mandate for NHS England for 2014/15, the Secretary of State for Health sets out an ambition for England to become one of the most successful countries in Europe at preventing premature deaths, and the objective for NHS England, working with CCGs, is to develop their contribution to the new system-wide ambition of avoiding an additional 30,000 premature deaths per year by 2020. Tackling premature deaths from cancer will be a key part of this.
- 2.22. The Mandate includes an objective for CCGs to demonstrate progress against the five domains of the NHS OF, and all of the indicators in the NHS OF – including, where possible, comparing our services and outcomes with the best in the world. Of particular relevance to cancer is an objective to prevent ill-health, and provide better early diagnosis and treatment of conditions such as cancer and heart disease, so that more of us can enjoy the prospect of a long and healthy old age. All five of the NHS OF domains are relevant to cancer patients and survivors.

Delivering public health programmes

- 2.23. PHE has responsibility for improving the general health of the public, and its responsibilities are set out in Framework Agreement between DH and PHE, which was published in November 2013.¹¹ Each year, DH and PHE will agree plans and deliverables to promote public health.
- 2.24. PHE has taken responsibility for certain parts of the national cancer programme 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 also has responsibility for piloting and roll out of new screening programmes and extensions to existing programmes. In addition, it has wide-ranging operational responsibilities for tackling smoking, alcohol misuse, obesity and physical inactivity, which are major contributors to cancer incidence.
- 2.25. NHS England directly commissions routine cancer screening programmes through an agreement with DH, based on evidence based specifications prepared by PHE. These specifications are part of an agreement on NHS public health functions 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

¹¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/259756/DH-PHE_FRAMEWORK_AGREEMENT_FINAL_VERSION_FOR_PUBLICATION_accessible.pdf

research activities. High level assurance of programme outcomes is conducted jointly by NHS England, DH and PHE. For 2014/15, the Section 7A agreement sets out expectations about moving forward in tackling areas with low levels of screening coverage.

Reducing premature mortality

- 2.26. In March 2013, the Department published *Living Well for Longer: a Call to Action on Avoidable Premature Mortality*.¹² This outlines our ambition to cut avoidable deaths from the five major causes – cancer, heart, stroke respiratory and liver disease – and to make England among the best in Europe.
- 2.27. In the *Call to Action* we set out how although great strides have been made in improving our health in recent years, we are not yet at the level of the best – too many people are still dying at too young an age. We want people right across society to live longer and to spend more of their lives in good health. In order to be successful, we will need to work across the three domains of prevention, early diagnosis and treatment.
- 2.28. We will set out a system response to this call in the form of a five year action plan early in 2014. This plan will bring together the actions DH, PHE and NHS England will take to reduce avoidable mortality.

New structures and partnerships

- 2.29. This report does not seek to describe the detail of the new structures, and how they work together in delivering improvements as agreed between DH, NHS England and PHE. Given, however, the very significant role played in the past by Cancer Networks, it seems appropriate for us to describe the role of the new Strategic Clinical Networks (SCNs).
- 2.30. NHS England hosts twelve SCNs which work across the boundaries of commissioning and provision and act as engines for change in the NHS. Their role is to support CCGs, Health and Wellbeing Boards (HWBs) and NHS England to make the best decisions about healthcare for the populations they serve by providing advice and leadership at a strategic level. SCNs are non-statutory organisations and have an annual accountability agreement, with NHS England.
- 2.31. There are four SCN groupings, which operate throughout the country and which cover: cancer; cardiovascular; maternity and children; and mental Health, dementia and neurological conditions. The four networks are geographically based on the 12 NHS England Clinical Senate areas.
- 2.32. The cancer SCNs have been developing their role over the past year. Their role has included working with the NHS locally to support the *Be Clear on Cancer* campaigns.
- 2.33. At national level, many elements of the cancer programme continue to be led as partnerships of organisations with a major interest in them. Elsewhere in the report we cover the partnerships on early diagnosis and survivorship, the National Awareness and

¹² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181103/Living_well_for_longer.pdf

Early Diagnosis Initiative (NAEDI) and National Cancer Survivorship Initiative (NCSI). In addition, many other elements of the work continues to be led by strong partnerships. For example, the National Cancer Equality Initiative (NCEI) continues as an NHS England work-stream, to support, inform and champion efforts to improve cancer outcomes by reducing inequality and promoting equality. It is co-chaired by the National Clinical Director for Cancer and the National Clinical Adviser for Equality and Health Inequalities, both in NHS England. The secretariat is provided by Macmillan Cancer Support. As regards the IOSC Implementation Advisory Group, we are still considering together how best to engage with stakeholders more generally.

Moving forward

- 2.34. This chapter reports on progress being made in relation to the Outcomes Frameworks and plans for further improvements in outcomes. While the general direction is a positive one, we recognise that there is a long way to go to match the best countries in the world. The recent EURO CARE5 publication in *The Lancet Oncology* in December 2013¹³, which shows our poor relative performance on cancer survival, looks at cancers diagnosed in the period up until 2007, but closing the gap remains a major challenge.

¹³ Cancer survival in Europe 1999—2007 by country and age: results of EURO CARE-5—a population-based study

[http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70546-1/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext)

3. Using intelligence to support improvements

Introduction

- 3.1. *Improving Outcomes: A Strategy for Cancer* set out information about the challenge of cancer and the scope to make improvements in services and outcomes; and showed how information could be used to drive improvements in outcomes. This chapter describes developments in the intelligence available.

Key data sets

Cancer Outcome and Services Dataset (COSD)

- 3.2. The Cancer Outcomes and Services Dataset (COSD – ROCR/OR/2142/FT6/001MAND) is the definitive national dataset for cancer and is designed to support consistency in data recording, data submission and outcomes analysis across NHS cancer services in England.
- 3.3. The COSD Information Standard (ISB1521 Amd 40/2012) mandated submission of the generic core dataset and site specific cancer stage data for all NHS providers from January 2013. Implementation of the Standard is phased, and since July 2013 all providers have been required to submit both the generic core dataset plus further site specific clinical items. A third phase from January 2014 will see the required submission of site specific pathology items (a subset of the Royal College of Pathologists minimum datasets). There is a comprehensive User Guide, detailing the phased implementation plan, available on the National Cancer Intelligence Network (NCIN) website.¹⁴
- 3.4. Despite the challenge presented by the large scale organisational changes across the NHS, significant progress has been made with the roll-out of COSD during 2013. In advance of implementation, the NCIN and National Cancer Registry Service (NCRS) teams collaborated with representatives from NHS providers to produce guidelines for monitoring conformance to the COSD Standard including details of the reporting feedback required.
- 3.5. Detailed reports based on post-registered data are expected to be available in the first quarter of 2014. The 2013 developments outlined here will lay stronger foundations for continuing to succeed in implementing the COSD standard through 2014 and beyond.

Chemotherapy – Systemic Anti-Cancer Therapy (SACT) dataset

- 3.6. The two year implementation period for the SACT programme finishes at the end of March 2014. The dataset covers the collection of treatment data on all adult solid tumours, haematology and paediatric chemotherapy. The majority of the 149 trusts

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http://www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset_cosd_latest_downloads

providing chemotherapy are fully engaged with the programme and submitting data on a monthly basis. The aim is to achieve full geographical coverage with all of the data fields completed by the end on the implementation period.

- 3.7. The Chemotherapy Intelligence Unit (CIU) is already providing analyses and reports both to the submitting trusts and to the wider clinical community. Reports on data completeness and quality are provided monthly and quarterly reports are generated demonstrating the patterns of chemotherapy for each tumour site both nationally and by individual provider. These reports can be viewed on the NHS website and a subset can be seen on the open website www.chemodataset.nhs.uk
- 3.8. The SACT database contained treatment records of over 132,000 patients by July 2013 with details of over 600,000 cycles of chemotherapy administered. Established analyses include: most frequently used regimens for tumour groups and individual tumours; benchmarking providers by patterns of treatment; and variations in treatment by age. More focussed analyses currently being developed include: mortality in relation to specific regimens and patient sub groups; dosage patterns of individual drugs; and body surface area by sex and tumour group.
- 3.9. The CIU is working with the NCRS to create a data exchange between the SACT system and the national registration system (ENCORE). This data linkage will allow the SACT system to access mortality and staging information that is vital to the analytical outputs for the CIU.

Radiotherapy Dataset (RTDS)

- 3.10. The RTDS¹⁵ now holds complete data for four consecutive years, provided and validated by the 50 NHS trusts which provide radiotherapy services. Summary data tables inform the quality measures of specialised commissioning, NCIN clinical interest groups and independent cancer research. Timely data relating to activity and services can be found in the NCIN Cancer Commissioning Toolkit (CCT).¹⁶ The newly established Radiotherapy Board uses the RTDS to monitor the recommended activity described in the 2007 National Radiotherapy Advisory Group report.¹⁷ A fourth version of RTDS will include teletherapy and brachytherapy.
- 3.11. Activity from RTDS shows a 10% growth in attendances and a 2.2% growth in episodes for the four year period it has been collected, with activity at 34,000 attendances per million population (pmp), compared with 31,000 in 2009 and 33,000 in 2010-11. RTDS is the definitive data source used to inform NHS England on the progress of Intensity Modulated Radiotherapy (IMRT) and the target of 24% set by the Radiotherapy Innovation Fund.

¹⁵ <http://www.natcansat.nhs.uk/rt/rtids.aspx>

¹⁶ <https://www.cancertoolkit.co.uk/>

¹⁷ *Radiotherapy: developing a world class service for England*, Report to Ministers from National Radiotherapy Advisory Group, DH 2007

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074575

[e/DH_074575](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074575)

- 3.12. An agreed code for the RTDS will be introduced for the emerging stereotactic radiotherapy, Stereotactic Brachytherapy (SBT) and Stereotactic Ablative Radiotherapy (SABR). A consequence of stereotactic radiotherapy is the reduction in the overall number of attendances required. This will need to be reflected in future radiotherapy activity recommendations where quality measures should be included in addition to total activity.

Diagnostic Imaging Dataset

- 3.13. The Diagnostic Imaging Dataset (DID) is a monthly data collection covering data on diagnostic imaging tests on NHS patients in England. It includes estimates of GP usage of direct access to key diagnostics tests for cancer. DID was a specific commitment of IOSC which has been successfully implemented, and in due course there will be a time series to show trends.
- 3.14. *Annual Diagnostic Imaging Dataset Statistics: April 2012 to March 2013*¹⁸ was published by NHS England in October 2013. For all imaging activity, over 36 million imaging tests were reported in England in the 12 months from April 2012 to March 2013. Plain radiography (X-ray) was most common, followed by ultrasound and computerized axial tomography (CT scan). However, there was wide variation between tests and between providers, as follows:
- The median period between the request being made and the test being performed varied greatly for the different tests
 - Across all types of imaging, emergency admissions and inpatients have shorter waits than outpatients and referrals made under GP direct access arrangements
 - There is variation in the period from a test being performed to the report being issued
 - For the key tests¹⁹ chest X-ray, brain MRI and non-obstetric ultrasound of the abdomen and/or pelvis, roughly a quarter of all tests that might have been used to diagnose or discount cancer were requested by GPs under direct access arrangements
 - The median period between the request being made and the test being performed varied between each of the key tests under GP direct access arrangements
 - With the exception of chest X-ray, for the key tests which may be used to diagnose or discount cancer, the median period from a test being requested to being performed is longer for GP direct access compared with all referrals. The main reason for this difference is that 'all referrals' includes tests on emergency admissions and inpatients, which have shorter waits.
- 3.15. Low use and delays in the delivery of diagnostic tests can cause problems for delivering earlier diagnosis and so these data are important for supporting further consideration about how diagnostic services can be more effective and to reduce variations.

¹⁸ <http://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/diagnostic-imaging-dataset-2012-13-data-2/>

¹⁹ Although these tests are used to diagnose cancer, many of the tests also have wider clinical uses. Within this dataset it is not possible to distinguish the different uses of these tests

Commissioners and providers may find the DID NHS iView²⁰ useful in their planning. We need also to consider how best to provide user-friendly information for GP practices about variations in use of diagnostic tests.

Recurrent and metastatic breast cancer data collection

- 3.16. The results from a joint project between Breast Cancer Care, the NCIN and the Association of Breast Surgery to collect data on recurrence/metastatic breast cancer have been encouraging, showing that collecting these data is both feasible and useful. The pilot demonstrated that 81% of the patients identified by the multi-disciplinary teams (MDTs) were also flagged through the cancer waiting times (CWT) process. Since April 2012, all breast units have been required to submit information on all patients diagnosed with a new recurrence or metastatic disease through the CWT process, and the submission of this information has been monitored by the project team.
- 3.17. In England as a whole, 7,176 patients were flagged on CWT as having been diagnosed or treated for recurrence/metastatic breast cancer at least once in 2012. We know from the West Midlands pilot that this is likely to be an underestimate because some patients will not be seen in hospital at all and some trusts do not, as yet, record recurrence/metastatic disease on the CWT system. Findings from the pilot suggest the actual figure could be between 12,000 and 16,000.
- 3.18. As originally planned, the work to collect data on recurrence/metastatic breast cancer needs now to be extended to consider how to collect similar data for all cancer types.

NCIN analysis to inform and drive change

Cancers diagnosed through emergency routes

- 3.19. Building on the routes to diagnosis work published in 2012, NCIN has updated and expanded their original analysis to include all patients diagnosed with cancer across a five year period (2006 to 2010). Results were published in December 2013 for 58 cancer sites and include many more of the rarer forms of cancer, including cancer of unknown primary. The summary data tables were put into the public domain as part of the on-going commitment to information transparency and include 2-year and 3-year survival as well as 1-year survival.
- 3.20. In May 2013, NCIN produced a data briefing looking in more detail at the proportion of patients presenting by the different emergency routes. The routes to diagnosis study showed that in 2006 to 2008, 24% of newly diagnosed cancers first presented into secondary care as an emergency presentation. The emergency presentation route comprises different emergency pathways into secondary care, including accident and emergency attendance, emergency GP referrals and emergency admissions to inpatients or outpatients.
- 3.21. In September 2013 a further routes to diagnosis paper examining emergency presentation of cancer and short-term mortality was published in a peer reviewed

²⁰ <https://iview.hscic.gov.uk/?aspxerrorpath=/>

journal.²¹ In summary, stage at diagnosis, age at diagnosis and the presence of co-morbidities were associated with a worse prognosis in the first year after diagnosis. Even adjusting for these factors, emergency presentation was associated with a worse prognosis in the first year after diagnosis.

- 3.22. NCIN have produced a set of proxy measures for emergency presentation using Hospital Episode Statistics (HES) data by cancer site at England level and by primary care organisation for all cancers combined. Analysis of emergency presentations is a useful proxy measure which commissioning and public health colleagues can now use closer to real time to monitor the effect of public health interventions, such as the *Be Clear on Cancer* campaigns. These data can be found on the NCIN website and are summarised for six of the common cancers (breast, bladder, colorectal, lung, pancreatic and prostate) and all cancers combined in Annex A.

Survivorship data

- 3.23. The development of robust data analysis is a crucial component of understanding the nearly two million people currently living with and beyond cancer in the UK and to inform our understanding of the cancer survivorship population. People surviving cancer will have very different levels of need and these needs are likely to change over time and depend on the type of cancer and treatment they have had. To make personalised care a reality, we need to understand the needs of the survivors, the health, social and economic impacts of cancer and the consequences of cancer treatment.
- 3.24. In partnership with Macmillan Cancer Support NCIN has published updated cancer prevalence data for all cancers combined (excluding non-melanoma skin cancer). Twenty-year prevalence data based on the number of people diagnosed with cancer in the period 1991-2010 and alive at the end of December 2010 were analysed by age, sex and different periods of time since diagnosis. The summary data tables were put into the public domain in December 2013 as part of the on-going commitment to information transparency and include results at UK level and by UK country. Annex B shows for England the number of people living with and beyond cancer by time since diagnosis and age at the end of 2010.
- 3.25. Evidence on the economic burden of cancer is limited due to the lack of reliable data on cost of care. In partnership with Imperial College London, City University London and Macmillan Cancer Support NCIN is developing a new dataset for England which links patient data in the National Cancer Data Repository with data on hospital activity and NHS costs. This will enable research on the magnitude and variation of cancer costs across different stages of the disease, geographical areas and pathways of care.
- 3.26. In collaboration with Macmillan Cancer Support, NCIN held a workshop in August 2013 with key people from each UK nation to help build a better understanding of what survivorship work is being done across England and the devolved administrations. The

²¹ Emergency presentation of cancer and short-term mortality (2013) McPhail S, Elliss-Brookes L, Shelton J, Ives A, Greenslade M, Vernon S, Morris EJ, Richards M. *Br J Cancer*. 109(8):2027-34. doi: 10.1038/bjc.2013.569

<http://www.ncbi.nlm.nih.gov/pubmed/24045658>

workshop identified actions that will support the UK nations to build a picture of the needs of people living with cancer, and a report drawing together the key themes and discussions will be published in 2014.

Equality

- 3.27. It is impossible to tackle inequalities without using data to inform activity and scrutinise progress. On behalf of the National Cancer Equality Initiative (NCEI), NCIN published *Cancer and Equality groups: Key metrics* in June 2013.²² The report sets out for the first time alongside each other a collection of cancer equality metrics covering: incidence; mortality; survival; ethnicity coding; screening; routes to diagnosis; patient experience; treatment; stage; and Patient Reported Outcome Measures (PROMs). Metrics are available for as many equality groups as the data currently allow.
- 3.28. The report shows that for some indicators such as ethnicity and staging, data completeness is improving although further and faster progress is urged. By presenting these data together in one place, with a commitment to updating these data annually, it is hoped that these data will provide a basis for further questions to be asked about inequalities in cancer, and to provide a platform to drive further analysis, especially in areas where the quality or completeness is improving. Annual publication will also enable us to track progress in improving cancer services and outcomes for everyone in England.
- 3.29. Inequalities in cancer incidence in relation to socio-economic deprivation are one of the major concerns of the NCEI as it is known that risk factors for cancer, especially smoking, are strongly influenced by socio-economic determinants. In partnership with Cancer Research UK, NCIN published summary statistics on its website in December 2013 describing the relationship between the incidence of and mortality from cancer in relation to socio-economic deprivation within England. The report and accompanying data tables provide analyses for patients diagnosed over a fifteen year period (1996 to 2010) for 36 of the more common cancer sites. Annex C shows the breakdown of incidence and mortality for all malignancies combined (excluding non-melanoma skin cancer) by socio-economic deprivation over this time period.
- 3.30. To coincide with a major workshop on men and cancer at the King's Fund in January 2013, a report presenting the current overall burden of cancer among males in the UK, and an outline of the extent of the differences between the sexes, was produced in collaboration with the Men's Health Forum, Cancer Research UK and NCIN. In general, adjusting for women's longer life expectancy, men are at significantly greater risk of both developing and dying from nearly all of the common cancers that occur in both sexes (with the exception of breast cancer). The report also highlighted that men of a working age, under 65, were 58 % more likely to die from cancers that affect both men and women. The King's Fund workshop also covered:
- Why the excess burden in men?
 - Do men present late or don't they?

²² http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality

- Are men biologically at greater risk?
- The role of infections.

3.31. The report of the workshop will be available on the Men's Health Forum website (www.menshelthforum.org.uk/).

Indicators and profiles

- 3.32. NCIN has continued to expand on its range of cancer profiles. 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 fourth version of the GP Profiles for Cancer, updated for December 2013, is now in the public domain as well as through the NCIN CCT. These Profiles give information about key indicators relating to cancer services for GP practices in England. They are intended to help GP practices think about the services they offer to their patients, in particular those services related to recognising symptoms and diagnosing cancer earlier.
- 3.33. NCIN have a planned programme to provide multidisciplinary team (MDT) based service profiles across a whole range of different cancer sites. Profiles for head and neck, gynaecology, oesophagogastric and sarcoma MDTs were published in September 2013 as a result of collaborative projects with regional Knowledge and Intelligence Team colleagues. These profiles bring together a range of outcomes and process information to provide comparative information for benchmarking and reviewing variation at acute trust or MDT level. Profiles for breast and colorectal cancer MDTs were published in March 2013 along with the first set of profiles for lung cancer MDTs.
- 3.34. Service profiles also provide evidence to support the clinical lines of enquiry that are now an intrinsic part of the National Cancer Peer Review Programme. Clinical lines of enquiry promote a stronger focus on clinical issues in order to make reviews clinically relevant and to sustain the continued support and involvement of clinical staff.
- 3.35. NCIN have been working with the Health and Social Care Information Centre (HSCIC) to define and test the cancer related indicators for use in the CCG 2014/15 Outcomes Indicator Set, including the percentage of patients diagnosed through emergency presentations and the percentage of patients diagnosed at an early stage of their cancer (stages 1 and 2).
- 3.36. A table summarising all NCIN analyses published in 2013 is at Annex D.

Making intelligence more accessible and user friendly

- 3.37. The NCIN together with the NCRS and other partners continues to develop its open access online learning programme called *Understanding Cancer*. This course, which is available through the NCIN website²³, currently provides around 40 modules on cancer and related issues to support staff and others interested in developing their understanding of this group of diseases. Each module has been developed and reviewed by clinical experts in the field and the course has been approved by the Institute of Healthcare Management.

²³ http://www.ncin.org.uk/cancer_information_tools/training/

- 3.38. The course is completely free to all UK users and up to September 2013 over 2,000 people had registered since it was launched in April 2012. The main aim of the programme is to provide free and accessible 'bite size' modules to improve understanding and thereby drive up the quality of data collection. Its principal users are MDT co-ordinators and other staff who manage the collection of data on cancer patients in NHS provider trusts, including non-clinical research staff, and cancer registration staff who collate and record cancer data within the registration service.
- 3.39. Nearly 40% of the registered users have so far completed at least one of the modules and successfully passed the related on-line assessment. Nearly a quarter of these users have completed at least ten of the modules, with the two most popular being Cancer Registration and Multidisciplinary Teams, reflecting the two main user groups.

National Cancer Registration Service

- 3.40. It is nearly twenty-four years since the Alberman Report for Office of Population, Census and Statistics (OPCS) recommended the formation of a single national cancer registry for England. With the completion over summer 2013 of the migration of all the English Cancer Registries to the new NCRS for England this has, at last, been achieved. The new unified registration service is part of Public Health England and collects data on all 350,000 new tumours diagnosed each year (including 75,000 non-melanoma skin cancers such as basal cell and squamous carcinoma) from the entire 52 million population of England. This achievement has only been possible with the hard work, commitment, skills and expertise of all the cancer registry staff and many other colleagues outside the organisation.
- 3.41. The NCRS now receives data directly from more than 500 local data systems, 12 national data feeds and includes cases from more than 1,400 weekly multi-disciplinary team meetings. Data comes from all 162 acute trusts and a range of private providers. Specialist teams in all the local NCRS offices work with each provider to ensure that the burden of data collection is minimal and that we use data that is part of their routine clinical processes or already collected as part of pre-existing data returns (for example Hospital Episode Statistics and the national cancer audits). When combined these sources deliver over 200,000 records each month and span pathology reports, patient administration data, imaging, and multi-disciplinary team meeting information. Details of treatments including radiotherapy, surgery and chemotherapy are also collected from other sources such as the SACT project and there are links to all three cancer screening programmes. Outcome data now includes the responses from Patient Reported Outcome Surveys and we have started work with palliative care teams to collect end-of-life care data.
- 3.42. In addition, the NCRS has imported all 11 million historical records that existed in the former regional registries and normalised the data from the various legacy classification systems that have been used over the years. The national childhood cancer registry in England is now supported by data flows directly from the paediatric oncology centres into the NCRS.

- 3.43. The registry teams have also been working closely with all acute providers to standardise the range of data items that flow to the registration service as part of the COSD. Work has focused on improving the quality of staging data on all stageable cancers; many providers now send high-quality staging data to the NCRS. Within the registry offices a cohort of cancer staging experts will oversee consistent cancer staging of 42 tumour sites. NCRS is on track to complete the Office for National Statistics (ONS) registration figures for 2012, and will have staged tumours in the major cancer sites by the start of 2014. However, it may take until the end of February 2014 for all finalised registrations for 2012 to be sent to ONS. The ambition is to have a monthly data cycle with quarterly publication.
- 3.44. Patient and clinician engagement is central to the NCRS. A partnership with Cancer Research UK and The Brains Trust has led to the development of a patient portal through which individuals can securely access and contribute to their own data held by the registry. The new national prostate cancer audit will collect all the patient-data directly through the NCRS, greatly improving the timeliness of the audit while reducing the direct demands on the NHS. Secure access to the data is through a new secure Cancer Analysis Service which has been built to provide data that meets with all the requirements of Caldicott 2.
- 3.45. The NCRS and the dataset that it collects is now the largest, most detailed and timely cancer data collection system anywhere in the world. It is a valuable national resource to support patient care, research, planning, public health, commerce and a wider range of cancer data requirements.

National cancer audits

- 3.46. The national cancer audits are funded by NHS England's National Clinical Audit and Patient Outcome Programme (NCAPOP) and commissioned by the Health Care Quality Improvement Partnership (HQIP). There are three active and long standing national cancer audits which monitor standards of care and outcomes for lung, colorectal and head and neck cancer patients, which have been collecting data for between 8 and 9 years. The coverage of NHS hospitals in England and Wales is now 100% and although the coverage of the incident patient population varies slightly between the audits, that too is approaching 100% for all three audits. The headline indicators for the quality of care have improved over time, most markedly in the lung cancer audit.
- 3.47. There is also a national audit of upper gastro-intestinal cancers, which is now in its third full year of data collection, and a new national prostate cancer audit commences data collection in 2014. Funding has been agreed for a new national breast cancer audit, which is expected to be commissioned formally in 2014. The lung, colorectal and head and neck cancer audits are currently funded until the end of 2014, with the expectation that a tendering process for their re-commissioning will be carried out early in that year. It is important for the re-commissioning of these audits that their future development takes into account the major changes in the NCRS and NCIN to ensure that they add significant value to what is emerging from these sources without adding a major burden of data collection to the NHS.

International Cancer Benchmarking Partnership

- 3.48. The International Cancer Benchmarking Partnership (ICBP) has undertaken and reported the most up to date international cancer survival comparisons. The results published in the Lancet (2011) showed that relative survival during 1995-2007 improved for breast, colorectal, lung and ovarian cancer patients in all jurisdictions.²⁴ However, the gap in survival between the best performing countries (Australia, Canada and Sweden) and the lowest (England, Northern Ireland, Wales and Denmark) remains largely unchanged, except for breast, where the UK is narrowing the gap.
- 3.49. Having established that English cancer survival estimates continue to lag behind the best performing countries in the partnership, the ICBP has continued investigating why these differences exist.
- 3.50. Subsequent studies on survival by cancer stage at diagnosis suggest that the UK's poorer survival could be down to a combination of more advanced cancer stage at diagnosis, unequal access to optimal treatment, sub-optimal staging of cancers which may influence treatment decisions and the impact of other long term illnesses.^{25 26 27 28}
- 3.51. The Partnership's research on the role of primary care in cancer diagnosis is nearing completion. This study is using case scenarios to identify how GPs in each country respond to patients with symptoms. It is also assessing differences in primary health care systems that affect investigation and referral of patients with possible cancer. This study will compare differences between countries in how GPs manage patients, access to diagnostics, the availability of advice from secondary care specialists and training to identify how these affect survival.
- 3.52. ICBP partners have also launched the first robust international comparison of the time intervals from first symptom(s) until diagnosis and start of treatment for cancer patients. This study is testing whether longer time spent on the cancer pathway to diagnosis contributes to poorer cancer outcomes. It will also describe and compare the various routes by which patients are diagnosed, including screen detected cancers, emergency presentations or symptomatic presentation to a GP, in order to identify possible targets for actions to reduce delays.
- 3.53. The initial ICBP benchmarking study found that differences in survival between countries were greatest within the first year of diagnosis, and that late stage at diagnosis correlates with an increase in excess mortality within the first few months after

²⁴ Coleman MP, Forman D, Bryant H et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* 2011, 377: 127-138

²⁵ Maringe C, Walters S, Butler J et al. Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership. *Gynecol Oncol.* 2012, 127:75-82

²⁶ Walters S, Maringe C, Coleman MP et al. Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom: a population-based study, 2004-2007. *Thorax.* 2013 Feb 11. doi: 10.1136/thoraxjnl-2012-202297

²⁷ Walters S, Maringe C, Butler J et al. Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom: a population-based study, 2004-2007. *Brit J Cancer.* 2013 Feb 28. doi: 10.1038/bjc.2013.6

²⁸ Maringe C, Walters S, Rachet B et al. Stage at diagnosis and colorectal cancer survival in six high-income countries: a population-based study of patients diagnosed during 2000-7. *Acta Oncologica.* 2013 April 15

diagnosis. The partnership has now launched the fifth study, identifying the factors that affect early mortality.

- 3.54. In addition to providing insight into the reasons underlying international differences in cancer outcomes, the ICBP is providing a framework for other researchers wishing to lead similar international collaborations. A paper in *Health Policy* (2013) describes how the ICBP can serve as a model for conducting international comparison studies relating to health policy.²⁹

Research

- 3.55. The Government has continued to invest in a wide range of research into the causes of cancer, prevention, screening, diagnosis, therapy and the organisation and delivery of services. Investment in cancer research by the National Institute for Health Research (NIHR) has risen from £101 million in 2010/11 to £133 million in 2012/13.
- 3.56. Through the NIHR Clinical Research Network (CRN), and in partnership with other research funders, the proportion of patients entering cancer clinical trials and studies is more than double that in any other country for which data exists, including the United States. Annual recruitment in England is nearly 100,000 patients.
- 3.57. The NIHR funds 14 Experimental Cancer Medicine Centres across England with joint funding from Cancer Research UK. These centres bring together laboratory and clinical patient-based research to speed up the development of new cancer therapies and individualise patient treatment. In 2012/13, the centres attracted over £16 million of new funding from commercial partnerships.
- 3.58. A collaboration between the NIHR Oxford Biomedical Research Centre and Oxford University and Hospitals Trust has resulted in the first multi-gene DNA sequencing test that can predict cancer patients' responses to treatment. The new test has been launched in the NHS and could save significant drug costs by getting patients on to the right treatments straightaway, reducing harm from side effects as well as the time lost before arriving at an effective treatment.
- 3.59. 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. In November 2013, the NCRI published an analysis of cancer research spend in the UK over the ten-year period 2002-2011.³⁰
- 3.60. Through the National Awareness and Early Diagnosis Initiative (NAEDI) and under the auspices of the NCRI, the UK Health Departments, Cancer Research UK and the Economic and Social Research Council are developing a portfolio of high quality

²⁹ Butler J, Foot C, Bomb M et al. The International Cancer Benchmarking Partnership: An international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom. *Health Policy*. 2013 May 18

³⁰ <http://www.ncri.org.uk/wp-content/uploads/2013/11/2013-NCRI-cancer-research-spend-Uk-2002-2011.pdf>

research projects in raising awareness and early detection of cancer. Following initial calls for research proposals in 2009 and 2010, a third call was launched in April 2013.

- 3.61. The James Lind Alliance is facilitating a large-scale Priority Setting Partnership, headed up by Marie Curie Cancer Care, to support end of life care research. The partnership is co-funded by the NIHR. This important collaboration will support the NIHR in developing research evidence to meet the needs of patients, carers, professionals and policy makers.

Information and research

Linking data held by cancer registries to research datasets and tissue samples

- 3.62. In 2012/2013, NCIN has been working with the UK Biobank on a pilot project to establish the mechanisms for the adjudication and phenotyping of cancer outcomes amongst their 500,000 participants. Through linkage to the National Cancer Data Repository, the pilot has enabled the identification of prevalent and incident cases, and the definition of an initial dataset for cancer cases for the England resident cohort. Over 9,000 incident cancer cases have been identified to date, making this an increasingly exciting resource for the study of cancer outcomes, exogenous and endogenous factors.
- 3.63. In the next year, the feasibility of obtaining additional clinical data and accessing diagnostic archival tissue held by NHS trusts to further enhance the data held on UK Biobank participants will be tested. This UK Biobank pilot project demonstrates the feasibility and added-value of linking cancer registration to large longitudinal cohort studies and tissue samples. NCIN will be taking forward lessons learned from this work to establish linkages with other large observational cohorts and tissue sample collections. At the same time, we will be intensifying our efforts in linking cancer registration to clinical trial data and identifying opportunities in this area.

New architecture, new datasets, new opportunities

- 3.64. With the migration of the English cancer registry data to one system now complete, and their linkage to new datasets, cancer registration in England continues to make a step change in the data available for research purposes. This also presents an opportunity for improvements to the processes by which this valuable resource is made available to researchers by developing a streamlined, timely and transparent service and an appropriate infrastructure to support it.

4. Prevention and early diagnosis

Introduction

- 4.1. Preventing more cancers from developing and diagnosing them at an earlier stage are essential to enable us to deliver our ambition to save an additional 5,000 lives. This chapter covers progress on major prevention programmes, and ground breaking expansions of our cancer screening programmes. We also report on the success of the *Be Clear on Cancer* awareness campaigns, describe some of the important work done and achievements in supporting primary care in diagnosing cancer earlier, and highlight challenges with endoscopy capacity.

Prevention

Human papilloma (HPV) vaccination

- 4.2. Published preliminary uptake data for HPV vaccinations given in the academic year 2012/13 up to June 2013 show that uptake in the routine cohort of Year 8 (12-13 year-old) girls for first (90.4%), second (88.6%) and third (80.8%) doses is continuing at high rates with only a minor decrease on last year's second and third dose uptake figures by an average of 1%. These remain some of the highest HPV vaccine uptake figures in the world. HPV vaccination has been included in the Public Health Outcomes Framework population vaccine coverage indicator.
- 4.3. In August 2012, the Joint Committee on Vaccination and Immunisation (JCVI) secretariat issued a call for evidence from interested parties on wider uses of vaccination against HPV infections, including new modelling work and economic analyses. In October 2013 JCVI reviewed the available evidence and agreed to the creation of a sub-committee on HPV vaccination. Any new proposals for vaccination of additional groups will require supporting evidence that this will be a cost effective use of resources. The Department anticipates JCVI recommendations in 2014 at the earliest.

Skin cancer

- 4.4. Cancer Research UK and the British Association of Dermatologists have developed a GP skin cancer toolkit, a suite of educational materials about identifying malignant skin lesions, which has been promoted via Doctors.net.uk. The results of the evaluation of the toolkit highlight that it has reached almost 10,000 GPs and helped to increase confidence in referring suspicious lesions. Qualitative feedback also emphasised the quality of the content and the value of the tool in GP continuing professional development.
- 4.5. DH has funded CRUK to continue to test approaches to encourage men aged 50 plus to visit their GP with signs of skin cancer. In autumn 2013 CRUK ran a campaign in South Devon, utilising text message communications, phone consultations with specialist nurses and volunteer community outreach to help address the barriers that prevent this audience from seeking advice about skin concerns.
- 4.6. Between 2003 and 2011, CRUK collected data via the Office for National Statistics (ONS) monthly omnibus survey to measure awareness, attitudes and reported

behaviour of adults in relation to sun protection. DH is funding a repeat of the survey in 2013 to enable CRUK to track changes over time.

Smoking

- 4.7. Effective tobacco control remains a priority and for the first time since records began, adult smoking rates in England are under 20%. This is in line with our national ambition to reduce rates of smoking by adults in England to 18.5% by the end of 2015. But smoking remains a significant cause of health inequalities and there is much variation in smoking rates across the country.
- 4.8. We continue to implement the Tobacco Control Plan to reduce the harm from tobacco, including for example, high profile marketing campaigns and local authorities, in their new public health role, commissioning stop smoking services to suit local needs:
- We are committed to completing the implementation of legislation to end the display of tobacco in shops. Since 2012, supermarkets (and other large shops) can no longer display tobacco. In 2015 small shops and all businesses selling tobacco to the public will need to cover displays of tobacco
 - Tobacco can no longer be sold from vending machines in England. This has removed a source of cigarettes that underage smokers could access easily. It was estimated that in England, about 35 million cigarettes were being sold to people under age of 18 every year
 - We have asked the eminent paediatrician Sir Cyril Chantler to carry out an independent review of the public health evidence on standardised tobacco packaging to report by March 2014
 - The Government will introduce standardised tobacco packaging if, following the review and consideration of the wider issues raised by this policy, we are satisfied that there are sufficient grounds to proceed
 - The Department has continued its programme of high profile stop smoking campaigns, including the hard-hitting New Year's health harms 'Mutation' campaign and Stoptober
 - In addition, in July, Public Health England ran a second TV-led marketing campaign on the dangers of secondhand smoke to children to encourage smokers to not smoke in the home or family car, for the health of their family
 - We continue to help those who want to quit. Since January this year, we have distributed over half a million Quit Kits. Local stop smoking services remain popular and effective³¹, with smokers four times more likely to quit successfully if they use local Stop Smoking Services than if they choose to go 'cold turkey'
 - To discourage smoking, we have some of the highest priced tobacco in Europe and will carry on with our high tax policy. This is coupled with an effective strategy, led by HMRC, to reduce the illicit tobacco trade.

³¹ West et al *Performance of English stop smoking services in first 10 years: analysis of service monitoring data* BMJ 2013;347:f4921

<http://www.bmj.com/content/347/bmj.f4921>

Obesity

- 4.9. The Government is committed to tackling overweight and obesity which is a major risk factor for certain cancers. In October 2011, we published *Healthy Lives, Healthy People: A call to action on obesity in England*³², which sets out national ambitions for a downward trend in overweight and obesity in children and adults by 2020.
- 4.10. From April 2013, local authorities are now responsible for tackling public health issues such as obesity, and they will be supported by national bodies, including PHE. PHE will help to provide evidence and advice, and create social marketing campaigns to support behaviour change.
- 4.11. This year Change4Life focussed on a number of campaigns aimed at providing people with information on the food they eat, encouraging people get more active, and using the start of the school term to encourage families to establish new healthier habits such as walking to school, and making sure children have a healthy lunch.
- 4.12. Under the Public Health Responsibility Deal businesses have agreed to sign up to pledges such as: the reduction of calories; the removal of trans fats; reduction of salt; increased uptake of fruit and vegetables; and calories labelled at out-of-home settings in order to inform customer choice. Information on how many businesses have signed up to these pledges is available at <https://responsibilitydeal.dh.gov.uk/>. In June, the Government published details of the new UK-wide front of pack labelling system to help consumers make healthier food choices.
- 4.13. We are continuing to invest in the School Games and Change4Life sports clubs which are targeting the least active children. There are now over 8,000 Change4Life sports clubs in primary and secondary schools. In addition, we announced an additional £300 million over two years to support primary school sport funding.

Alcohol

Minimum Unit Pricing

- 4.14. Between November 2012 and March 2013 the Government held a public consultation on a number of aspects of the Alcohol Strategy, including an appropriate level for setting a Minimum Unit Price for alcohol.
- 4.15. The Government's response, published on 17 July 2013, announced that Minimum Unit Pricing would not be taken forward at the present time to allow for the collection of further empirical evidence. It made clear that the Government is not rejecting Minimum Unit Pricing, merely delaying it while further empirical evidence becomes available, which we will then consider carefully.

³² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213720/dh_130487.pdf

Public Health Responsibility Deal – Alcohol Network

- 4.16. Through the Responsibility Deal we are working with around 125 alcohol retailers and manufacturers to help improve public health by helping people drink within the guidelines.
- 4.17. Over 30 alcohol retailers and producers have pledged to remove one billion units of alcohol from the market (around 2%) by the end of 2015. This is expected to result in many hundreds fewer alcohol-related deaths; many thousands fewer hospital admissions; and a reduction in alcohol-related crime.
- 4.18. The Responsibility Deal alcohol network is delivering on basic issues such as providing consumer information in a zero cost, zero regulatory burden way for example, 92 companies are committed to having 80% of bottles and cans displaying unit and health information and a pregnancy warning by the end of this year and 70 pub chains and retailers pledged to display unit and health information.
- 4.19. The Government's response to the recent alcohol strategy consultation set a challenge to industry to deliver rapid action, through the RD, in the following areas:
- tackling the high strength or high volume products that can cause the most harm
 - promoting and displaying alcohol responsibly in shops
 - improving education around drinking
 - supporting targeted local action.
- 4.20. Industry has agreed to come back to Government with a delivery plan by the end of the year.

Treatment and targeted interventions

- 4.21. Local areas are best placed to tackle alcohol-related issues in ways that suit local needs.
- 4.22. It is important for the health service to identify those at risk and provide evidence-based brief advice and support. From April 2013, an alcohol risk assessment has been incorporated into the NHS Health Check for those aged 40 to 74 and has the potential to reach 3m adults every year.
- 4.23. A survey has been commissioned by PHE to map the spread and scope of the service and work by Alcohol Liaison nurses. This work will determine the clinical effectiveness and cost effective models of the services available, which will be taken forward to inform local commissioning groups.
- 4.24. PHE is developing a model pathway to reduce under 18 year olds' alcohol related A&E attendances. They have been working with an expert group who has collated sample pathways from all over England. Model pathways and guidance are being drafted for publication by March 2014.
- 4.25. There are currently eight pilots implementing Payment by Results (PbR) for drugs and alcohol dependency. Lessons learned from the pilots will be disseminated to help the wider treatment community.

Chief Medical Officer's review of the drinking guidelines

- 4.26. The Government's Chief Medical Officer, Dame Sally Davies, along with the CMOs of Scotland, Wales, and Northern Ireland, is overseeing a review of the evidence on alcohol guidelines. The review was announced in March 2012 as part of the Government's response to the House of Commons Science & Technology Committee's recommendation for such a review. Dame Sally has set up two expert groups:
- On the evidence of risks to health from alcohol
 - On evidence for the impact of guidelines on behaviour
- 4.27. The expert groups will report by January 2014. If agreed by the CMOs, a second phase of work will then begin to develop new guidelines. This will conclude in July 2014.

Occupational cancer

- 4.28. Occupational cancer continues to be the major cause of occupational ill-health accounting for over 20 million working days lost and approximately 8000 deaths with a further 14,000 cancer registrations annually.
- 4.29. The Health and Safety Executive (HSE) is committed to reducing these numbers and in March 2013 hosted a workshop, which brought together a range of organisations, and key players who were invited to discuss and develop new and innovative ways of tackling occupational disease issues with a particular focus on occupational cancer.
- 4.30. The event was designed to explore what more others in the health and safety system could contribute to future interventions. As well as encouraging others to take action, HSE is also taking forward a number of work strands to continue the momentum. This work includes, setting up an occupational disease web community to encourage the promotion and exchange of ideas and initiatives for tackling occupational disease. The community will be open to anyone who has an interest in reducing the incidence of occupational disease and wish to promote their work or seek and develop ideas.
- 4.31. Tackling occupational cancer is particularly complex and no common approach can be used to deal with all of the issues involved. HSE continues to take forward a range of other activities that are designed to specifically address priority carcinogens and/or occupations that generate them, such as interventions with stakeholders, targeted inspection initiatives and awareness raising activities.³³

Aspirin

- 4.32. An international consensus statement on the prophylactic use of aspirin in the general population has been developed by experts around the world, but is awaiting publication. The statement is likely to say that accumulating evidence supports an effect of aspirin in

³³ Information collated by HSE from information the Labour Force Survey, The Health and Occupation Reporting network, the Surveillance of Work-related and Occupational Respirator Disease specialist surveillance scheme and findings from the 2011 Cancer Burden Study

reducing overall cancer incidence and mortality in the general population, and these benefits are larger and most clearly established for some gastrointestinal cancers.

- 4.33. Once the international consensus statement is published, we will assess what this 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.
- 4.34. CRUK has identified six unanswered research questions on aspirin and cancer:
- How long people should take aspirin for
 - What age people should start taking it
 - What the optimal daily dose is
 - Whether some people are more likely than others to get side effects
 - Whether some people will benefit and others won't
 - Whether we can lower the risk of having a stroke when people stop taking aspirin.

Extending and expanding the cancer screening programmes

Breast cancer screening

- 4.35. As at October 2013, 61 out of 80 local programmes (76%) had entered the breast screening age extension randomisation trial to women aged 47-49 and 71-73, and a further nine (11%) which are unsuitable for randomisation were inviting only the 47-49 year-olds. Over a million women have been randomised as part of the trial so far. Results of the impact on breast cancer mortality rates will be known in the early 2020s.
- 4.36. 10 local programmes (12.5%) are still to expand, citing lack of digital mammography (DM) equipment, staffing shortfalls and lack of funding as issues. As at October 2013, 78 (98%) of local programmes had at least one direct DM x-ray set and 69 (86%) were fully digital. There are currently two local screening programmes without any digital equipment, Worthing and Cumbria. The Worthing programme will be moving to a new purpose built unit with DM at the end of December 2013. North Cumbria has no firm date for implementation of DM.

New information materials

- 4.37. The NHS Breast Screening Programme began to use a new invitation letter and accompanying leaflet in September 2013.³⁴ The new materials support the on-going commitment to enable women to make an informed choice about whether or not to attend their breast screening appointment. The updated leaflet incorporates the findings of the Independent Breast Screening Review, led by Professor Sir Michael Marmot and published in October 2012.³⁵

³⁴ *NHS breast screening: Helping you decide*, NHS Cancer Screening Programmes (September 2013)

<http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp.pdf>

³⁵ The Independent Review on Breast Cancer Screening, *The Benefits and Harms of Breast Cancer Screening*, October 2012

http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/breast-screening-report.pdf

- 4.38. NHS Cancer Screening Programmes commissioned King's Health Partners (a partnership of public sector academic and NHS organisations) to develop a new process for producing materials across all the screening programmes and then to design information for each programme explaining the benefits and risks of attending for screening.
- 4.39. A public consultation on all cancer screening information was held, to which more than 1,000 members of the public and 50 people with a professional interest in the subject responded. The new leaflets provide a balanced assessment of the benefits and risks of cancer screening, giving people the clear, accurate information they need to make a personal decision about whether to attend for screening.

Cervical screening

- 4.40. As at the end of September 2013, 97.5% of women were receiving their cervical screening test results within 14 days, against an operational standard of 98% (as recommended by the Advisory Committee on Cervical Screening).

HPV testing as triage and test of cure

- 4.41. HPV testing as triage (sorting) for women with mild or borderline cervical screening test results has been piloted and shown to be effective. HPV testing can also be used to test whether women who have had cervical abnormalities treated have been cured and this has been shown to be effective. All local screening services have been cleared to implement HPV testing. In year one of implementation (2012/13), HPV testing for triage was conducted on the first occurrence of low grade abnormalities in eligible women routinely invited for screening along with test of cure for newly treated women with normal or low grade abnormalities six months after treatment. In year two of implementation (2013/14) HPV testing as triage is being extended to all women with low grade abnormalities and test of cure extended to all women treated for abnormalities who have normal or low grade abnormalities six months after treatment. HPV testing as triage and test of cure has now been included in the cervical screening specification to the revised Section 7a agreement between the DH and NHS England, and will become routine from 2014/15.

HPV Testing as Primary Screening (HPV TaPS)

- 4.42. The UK National Screening Committee has given its support for a pilot to assess the value of using HPV TaPS for cervical disease, rather than the currently used cytology test. The pilot programme began in May 2013 and is now operating at six sites: Liverpool; Manchester; Northwick Park (Harrow); Bristol; Sheffield; and Norwich. This is potentially a huge change to the programme, so the pilot will run for at least three years in order to determine a safe and practical pathway for the programme. A formal evaluation of the pilot will take place and, if results show it is successful, we will roll out HPV TaPS across England, probably from 2017/18. Cancer Research UK have estimated that, when fully implemented, HPV TaPS could prevent an additional 600 cancer a year.

Bowel cancer screening

- 4.43. As at the end of November 2013, nearly 21 million home testing kits had been sent out since the NHS Bowel Cancer Screening Programme began in 2006 and over 12 million had been returned completed.
- 4.44. Over 17,500 cancers had been detected, and over 95,000 patients had been managed for polyps, including polyp removal. Men and women over the age limit can request a testing kit every two years, and over 240,000 have self-referred for screening so far.
- 4.45. The age extension of the programme to men and women aged 70 to their 75th birthday is nearing completion. As at December 2013, 57 of the 58 local screening centres (98%) had implemented the extension. The last centre yet to implement age extension is Harrogate, Leeds and York. The extended age range has now been included in the bowel cancer screening specification attached to the revised Section 7a agreement between the DH and NHS England, and will become routine from 2014/15.

Faecal Immunochemical Testing (FIT)

- 4.46. The original Strategy set out how NHS Cancer Screening Programmes will be looking at how the more accurate and easier to use Faecal Immunochemical Test (FIT) can be introduced into the programme potentially to increase uptake and to provide more accurate results. A protocol has been devised to pilot FIT within the programme to assess the feasibility, practicality and cost-effectiveness of moving to this technology.
- 4.47. NHS Cancer Screening Programmes will be piloting FIT from spring 2014. The IT software is being written, along with a protocol for evaluation. The pilot will involve 40,000 people spread over six months in many screening centres, rather than just a few pilot sites. We hope this will give us a quicker and very robust answer so that decisions can be made on whether to roll-out FIT across the whole programme as soon as possible.

Bowel Scope Screening

- 4.48. Research has shown that a one-off bowel screening procedure using flexible sigmoidoscopy (bowel scope screening) could save 3,000 lives a year.³⁶ The IT system to support the new NHS Bowel Scope Screening (BSS) programme was delivered in March 2013, when the pilot began inviting men and women aged 55 for BSS. The six pilot sites are: Norwich; South of Tyne; St Mark's, London; Surrey; West Kent; and Wolverhampton.
- 4.49. As at 31st October 2013, over 5,000 invitations had been issued and over 2,300 procedures performed. Uptake stood at 42.7%, and ranged from 33% in the lowest site to 51% in the highest. 3.2% of people were being referred to colonoscopy following BSS, and over 650 polyps had been retrieved over all.

³⁶ The Lancet, Volume 375, Issue 9726, Pages 1624 - 1633, 8 May 2010

4.50. PHE are confident that, in addition to the six pilot sites, at least 12 Wave 1 sites will have rolled out BSS by the end of March 2014, meeting the 30% commitment in the original Strategy. The Section 7a Agreement between the Department and NHS England states that PHE will continue to be responsible in 2014-15 for the roll out of the BSS programme which will contribute towards the Mandate objective for England to become one of the most successful countries in Europe at preventing premature deaths. The Secretary of State's commitment is to have this programme rolled out to 60% of England by the end of March 2015, and to the rest of England by the end of 2016. NHS England will work with PHE to help deliver the involvement of screening centres sufficient to meet the 60% commitment and to support preparatory steps in other bowel cancer screening centres to implement by the end of 2016.

Screening for other cancers

Prostate cancer screening

4.51. The latest data from the European Randomised Study of Screening for Prostate Cancer (ERSPC) with 11 years follow-up was published in the New England Journal of Medicine in March 2012.³⁷ This data showed that death rates from prostate cancer were 21% lower among participants who were given Prostate Specific Antigen (PSA) screening. However, to prevent one death from prostate cancer at 11 years of follow-up, 1,055 men would have to be invited for screening and 37 cancers would need to be treated.

4.52. On behalf of the UK National Screening Committee (UK NSC), the School of Health and Related Research (SchARR) at the University of Sheffield developed a prostate cancer screening model, reported as *Option appraisal: screening for prostate cancer*.³⁸ Based on the ERSPC 11 years follow-up data, SchARR reprogrammed and recalibrated the prostate cancer screening model. The report *Option appraisal: screening for prostate cancer, Model update*, published in March 2013, concluded that:

- A single screen at age 50 has little long term impact on overall age specific prostate cancer incidence and mortality rates
- Intensive annual screening has little marginal benefit over a policy of screening every two years
- Screening policies every two and four years are estimated to impact on early diagnosis and stage at diagnosis of prostate cancer
- In order to obtain one additional year of life the modelling suggests that the repeat screening policies are associated with 22-32 years of additional prostate cancer management (17-30 years for a single screen at age 50)
- Despite the impact on stage at diagnosis, trials do not demonstrate any overall survival benefit from screening
- Radical treatment would increase up to three times for a repeat screening policy, with incidence of side effects rising accordingly
- Quality Adjusted Life Years (QALYs) are negative for all screening policies,

³⁷ Schroder et al. Prostate-Cancer Mortality at 11 Years of Follow-up. *N Eng J Med* 2012; 366:981-90

³⁸ <http://www.screening.nhs.uk/prostatecancer>

- meaning the harms of side effects outweigh any potential survival benefits
- Costs would vary from £58 million a year for a once only screen at age 50, rising to over £1 billion for an annual screening policy.

- 4.53. As a result, the UK NSC does not recommend screening men for prostate cancer because the risks of over-diagnosis far outweighed any potential reduction in mortality. However, there is a considerable amount of research ongoing to develop tests that can distinguish between indolent and aggressive disease, which may in the future change the overall cost-benefit benefit-risk profile and lead to a feasible, effective screening programme.
- 4.54. PSA testing can, of course, be performed on request. Information is provided on the risks and benefits by the Prostate Cancer Risk Management Programme³⁹.

Lung cancer screening

- 4.55. One major US trial has shown a 20% reduction in lung cancer specific mortality using low dose spiral CT as the screening tool. The results of both a major European trial and the UK Lung Cancer Screening pilot study are expected to be published in 2015 and it is at that stage that we hope to be in a position to properly consider the feasibility and cost-effectiveness of a CT screening programme for lung cancer in the UK.

Ovarian cancer screening

- 4.56. The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) began in 2000, and 200,000 post-menopausal women aged 50 to 74 have been randomised in 12 UK centres. Half the women are being screened, either by annual CA125 blood test or annual trans-vaginal ultrasound, with the remainder as the control group. The study is being funded by the Medical Research Council and Cancer Research UK, with the Department of Health providing the NHS costs for the study. The study is expected to cost some £20 million, with final results known in 2015.

Be Clear on Cancer campaigns

- 4.57. In partnership with DH and NHS England (including NHS Improving Quality), PHE has taken on the running of the *Be Clear on Cancer* (BCOC) campaigns to highlight the symptoms of a range of cancers and to encourage people with the relevant symptoms to visit their GP. Cancer Research UK (CRUK) is providing elements of programme management, social marketing support and evaluation of the 2012/13 campaigns. In 2013/14, evaluation of the campaigns is transitioning over from CRUK to the National Cancer Intelligence Network (NCIN) in PHE, which will formally take on the evaluation of the 2013/14 campaigns.
- 4.58. The 2013 campaigns have included:
- A repeat of the national lung cancer campaign from July to mid-August 2013
 - A regional pilot campaign for kidney and bladder cancers (“blood in pee”) from

³⁹ <http://www.cancerscreening.nhs.uk/prostate/index.html>

January to mid-March 2013, which proved successful and led to a national campaign of “blood in pee” from mid-October to November 2013

- A regional pilot campaign on breast cancer in women over 70 from January to mid-March 2013
- A new local pilot campaign for ovarian cancer and a new symptoms campaign, *Know4Sure*, to raise awareness of four key symptoms common to many cancers, including rarer cancers (unusual bleeding, lumps, pain or weight loss) from January to mid-March 2013
- Extending the “top-up” bowel cancer campaign in regions of the country between September 2012 to mid-March 2013.

- 4.59. For the campaigns we will run in early 2014, we announced in September 2013 that the next national BCOC campaign will raise awareness of breast cancer in women over 70. This campaign has been piloted at local and regional levels, and a national campaign will run from early February to mid-March 2014, featuring TV ads to reinforce the message that one in three women who get breast cancer are aged over 70.
- 4.60. We also announced that we will be running two regional awareness campaigns on ovarian cancer and oesophageal cancers between February and March 2014. Both regional campaigns will feature TV advertising, with the ovarian cancer campaign being run in the North West TV region, and the oesophageal cancer campaign in the North East and Borders TV regions.
- 4.61. The local ovarian cancer campaign, which ran early in 2013 and targeted women aged 50 years and over, focused on the key symptom of bloating, encouraging women who experienced this for three weeks or more to tell their doctor. Similarly a local oesophago-gastric pilot campaign ran in 2012, targeting men and women aged 55 and over and highlighted the key symptoms of difficulty swallowing and heart burn/indigestion for three weeks.
- 4.62. We will also re-run the highly successful national lung cancer campaign in spring 2014, along with a local pilot campaign in the South West of England on awareness of the symptoms of skin cancer. Decisions and announcements on further BCOC activity later in 2014 will be made in due course, based on evaluation and evidence.
- 4.63. Full resources for all the campaigns can be found on the National Awareness and Early Diagnosis Initiative (NAEDI) website.⁴⁰ We will continue to support NAEDI, with the Chief Executive of CRUK and the National Clinical Director for Cancer in NHS England as co-chairs, with CRUK providing the secretariat.

Evaluation of cancer awareness campaigns in 2012 and 2013

- 4.64. 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

⁴⁰ <http://www.cancerresearchuk.org/cancer-info/spotcancerearly/naedi/beclearoncancer/beclearoncancer>

activity. Information on the number of cancers diagnosed and staged are also important metrics, but these data take longer to come through, due to their nature.

- 4.65. Decisions on which campaigns to run and at what level are based on the results of this evaluation. We decided to repeat the national lung cancer campaign as analysis of the pilot in the midlands found a 14.0% significant increase in lung cancer cases diagnosed for the period October to December 2011 when the campaign ran, compared with the same period in the previous year. The control trusts only saw a 4.7% increase over the same period, which was also statistically significant.
- 4.66. Comparing the same periods, there was also evidence of a shift in stage at diagnosis for pilot trusts which was not found for control trusts. The proportion of small cell lung cancers (SCLC) staged as “extensive” saw a statistically significant fall from 74.1% to 63.4, hence those with “limited” disease increased from 25.9% to 36.6%. There was also a trend towards earlier stage at diagnosis of non-small cell lung cancer (NSCLC). Furthermore, pilot trusts saw a statistically significant increase in surgical resections as the first definitive treatment (from 12.4% to 16.0%) whilst no significant change was seen in control trusts. For the pilot trusts, one-year survival statistically significantly increased from 35.2% to 39.2% whereas the increase for the control trusts was smaller (from 37.3% to 39.3%), but still statistically significant.
- 4.67. Initial results from the first national lung campaign in 2012 showed significant increases in unprompted awareness of symptoms amongst the target audience, and a significant increase of approximately 30% in two week wait (2WW) referrals for suspected lung cancer in the campaign months, which in turn led to extremely positive changes in the number of cancers diagnosed, stage and treatment of lung cancers within the campaign period.
- 4.68. There was a statistically significant increase of 9.1% in the number of lung cancers diagnosed in patients first seen for lung cancer during the campaign months (May-July 2012) in comparison to the same months in 2011, whilst the increase for the control period (February-April 2011 compared to February-April 2012) did not reach statistical significance. There was also a statistically significant shift towards an earlier stage distribution for Non-Small Cell Lung Cancers (NSCLCs - including carcinoid tumours) over the campaign months in comparison to the same months the previous year, which was not seen for the control months. There was a statistically significant increase of 2.3 percentage points for the proportion of patients receiving surgical resection as a first definitive treatment for those first seen for lung cancer during the campaign months in comparison to the same months in the previous year, whilst there was no statistically significant change in this proportion during the control period.
- 4.69. The decision to go national with the BCOC “blood in pee” (bladder and kidney cancer) campaign was based on the results from three local pilots in 2012 which showed a 7.4% significant increase in cystoscopy procedures (based on analysis of DM01 analysis) in the pilot areas compared to a 0.9% significant decrease in the control area, and a 26% significant increase in 2WW referrals for suspected urological cancer in the pilot area compared with an 18% significant increase in the control area (when comparing the campaign period with the same period in the previous year).

- 4.70. In the early 2013 regional pilot of “blood in pee”, the percentage of responders saying they would see their GP the same day if they noticed urological changes increased significantly from 18% to 27%. Knowledge of the symptom of “blood in pee” for bladder and kidney cancer rose significantly from 41% to 65%, and there was a 28% significant increase in 2WW referrals for suspected urological cancer in the pilot areas compared with a 9% significant increase in the control areas. Further evaluation data has shown that this campaign appears to have improved the detection rate for urological cancer. Overall, the detection rate increased, significantly, by 5 percentage points in the site-specific campaign area, compared with an increase of 2 percentage points in the control areas.
- 4.71. The national BCOC breast cancer in women over 70 campaign will start in February 2014, based on results from the local and regional pilot campaigns. In the local pilots there was an 8% significant increase in 2WW referrals for malignant breast cancer and non-cancer symptoms in women over 70 compared to a 5% significant increase in the control area. A 4% increase in breast cancers diagnosed following a 2WW referral for non-suspected cancer symptoms in women over 70 compared to a 2% increase in the control area was also seen. In the regional campaign, which ran from January to March 2013, the belief that one in three women who get breast cancer aged over 70 increased significantly from 16% to 25%. Overall 37% of women over 70 recalled receiving a direct mail pack if sent one, and for women aged 70-79 there was a 13% significant increase in referrals for suspected breast cancer in the pilot region.
- 4.72. The local BCOC ovarian cancer campaign (“feeling bloated most days for three weeks”) will go regional from February 2014 based on evidence from the 2013 local pilot, which showed that spontaneous awareness of bloating for 3 weeks or more as a symptom of ovarian cancer increased significantly from 16% pre-campaign to 28% post campaign in the pilot areas. Also, 57% of women agreed that the campaign “told them something new”, a very high figure.
- 4.73. Likewise, the local BCOC oesophago-gastric cancer campaign (“indigestion or heartburn most days for three weeks”) will also go regional from February 2014 based on evidence from the 2012 local pilot, with the number of oesophageal cancers diagnosed following a 2WW referral for suspected upper GI cancer increasing by 20% in the pilot area compared with 3% in the control area (when comparing the campaign months with the same period in the previous year). Although this wasn’t statistically significantly higher in the pilot area, this could be due to the size of the pilot area.
- 4.74. The results for the local *Know4Sure* BCOC campaign in early 2013 were less clear, with not enough evidence enabling it to progress to a regional campaign. There were positive aspects to the multi-symptom approach, but still some areas that require further investigation, such as which communication channels are best for this more generic approach, and possibly refining the key message. Materials are still available on the BCOC website should any local teams wish to use them.
- 4.75. We are hoping to continue the BCOC campaigns into 2014/15, and decisions on what campaigns to run will be based on the evidence and learning from the evaluation of the impact of all the campaigns so far. We will continue to keep these campaigns under

review and work with relevant experts to see what might be done to tackle other cancer types.

Reducing inequalities in raising awareness of cancer symptoms

- 4.76. The BCOC campaigns have been largely aimed at people aged over 55 and at lower socio-economic groups (C2DE), where the most improvements in outcomes can be made.
- 4.77. The first national bowel cancer campaign, which ran from January to March 2012, showed higher increases in attendance in GP practices in areas of high deprivation (46%) than those in areas of low deprivation (24%). This is based on the nine weeks from the start of the campaign in 2012 with the same period in 2011.
- 4.78. The campaigns are reaching older audiences, even when age is not stipulated in the key message. When comparing the campaign months with the same months in the previous year, the regional lung pilot saw a significant change in the age distribution of those diagnosed with lung cancer that was not seen in the control area. In the pilot trusts there was a significant increase in the proportion diagnosed at 85 years or older (9.6% to 11.9%) which was not seen in the control trusts.
- 4.79. With each campaign, a range of activity takes place to reduce inequalities. For the BiP campaign in autumn 2013, the BBC agreed to show signed versions of the television advertisements around its programming schedule for the hard of hearing. Easy read versions of leaflets were developed, along with versions in Braille, audio, and large print on-line for the visually impaired.
- 4.80. Although the BCOC campaigns use everyday language to help people feel more comfortable when discussing symptoms with their GP, we know there are cultural, religious and language barriers preventing some Black and Minority Ethnic (BME) groups from presenting early to their GPs. To counter this, PHE works with a specialist multicultural marketing consultancy to develop activity with BME groups.
- 4.81. During recent national campaigns there has been targeted TV, radio and press advertising in key national and regional black and South Asian media. As part of the BME PR activity healthcare professionals and cancer survivors from ethnic minorities where possible, are recruited to participate in media interviews to address the cultural, religious and language barriers preventing early presentation to GPs. These discussions take place in ethnic languages where appropriate. National campaign symptom cards are translated into Urdu, Bengali, Gujarati and Punjabi and are available for organisations to print and distribute accordingly.
- 4.82. With a grant from DH, Cancer Equality were able to fund 44 organisations to raise the awareness of cancer as part of Ethnic Minority Cancer Awareness Week (EMCAW) in July 2013. Events took place in London, Peterborough, Manchester, Sheffield, Gloucestershire, Ipswich and Birmingham. A detailed evaluation report is being produced, which will include: activity feedback from community groups; opinions of health professionals who were involved; and focus groups on the impact activities had on raising awareness.

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

Clinical decision support tools

- 4.83. In 2013, Macmillan Cancer Support, partly funded by DH, piloted an electronic cancer decision support tool for GPs to use in their routine practice. The tool helps GPs identify patients whom they might not otherwise refer urgently for suspected cancer. It 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).
- 4.84. 502 GP practices across England participated in the pilot. A full evaluation of the pilot will be undertaken by CRUK and the DH Policy Research Unit. Initial indications are that the cancer decision support tool influences a GP's decision in around half of the occasions in which it is used. Macmillan Cancer Support is working with GP IT software companies to further develop, promote and disseminate versions of the tool.

Significant Event Audits (SEAs)

- 4.85. The Royal College of General Practitioners (RCGP) Clinical Innovation and Research centre, in partnership with Macmillan Cancer Support, is completing the piloting of 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.

Primary care engagement pilot

- 4.86. CRUK have continued this work and now have two pilots, one in London covering three Clinical Commissioning Groups (CCGs) and one across Merseyside and Cheshire. The plan is to expand this work with additional funding from NHS England focussing on early diagnosis and uptake of screening. The work with GPs uses practice profiles to provide insight into current activity. This work also links with the SEA's and risk assessment tools (RATs) to create a complete picture of activity across a cancer pathway.

On-line learning for GPs

- 4.87. An on-line learning tool for GPs supported by DH and developed by BMJ Learning was launched in September 2013, with the first of four modules to support earlier diagnosis of cancer. The modules focus on:
- Tackling late diagnosis
 - Diagnosing osteosarcoma and brain tumours in children and young people (with an additional section on communication skills)
 - Risk assessment tools
 - The cancer pathway and the role of primary care.
- 4.88. The modules offer accredited professional development and are one of a number of such resources available for GPs.

Cancer Network GP leads

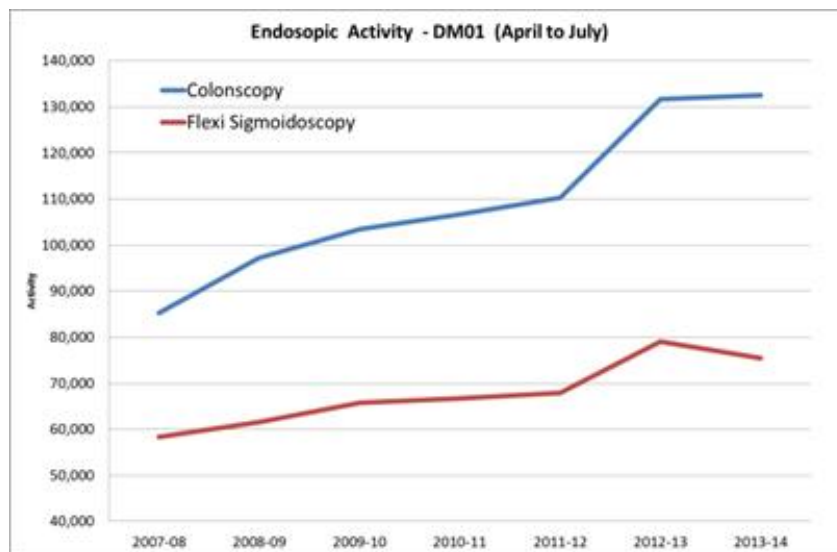
- 4.89. GP leads are working with practices on early diagnosis of cancer, using the practice profiles, audit and SEAs, delivering training and education events and raising the importance of early diagnosis of cancer with commissioners and primary care teams.

Throughout the transition to Strategic Clinical Networks, this work has been continued with support from CRUK. Participation has continued to be strong for activities linked to the local, regional or national *Be Clear on Cancer* symptom awareness campaigns, including practice preparation for the public response.

Endoscopy

- 4.90. Endoscopy capacity remains a significant challenge, especially for the delivery of Bowel Scope Screening. In order to inform priorities, NHS England have analysed current endoscopy activity and updated the original 2011 analysis of growth in demand.
- 4.91. Up to April 2013 total lower gastro-intestinal (GI) endoscopic activity grew in line with the 2011 forecast that at least a 10% annual growth in activity was required between 2011/12 to 2016/17. Early results from the waiting times returns (DM01) suggest that demand growth in the first four months of 2013/14 for the two main lower GI endoscopic investigations may have levelled off or reduced – see Figure 4.1. This analysis permits early year-on-year comparisons to be made but must be viewed with caution at this stage.

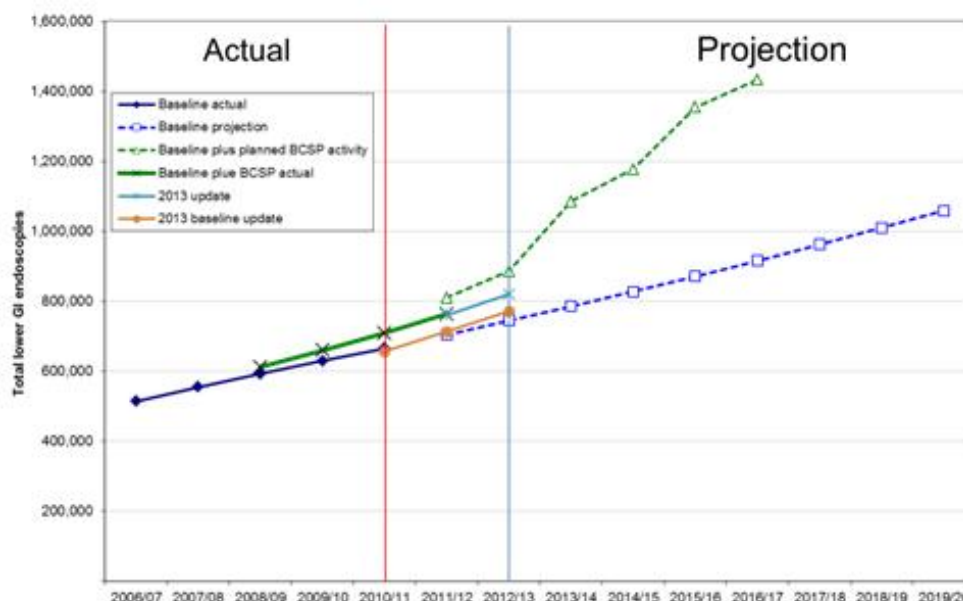
Figure 4.1 Total activity for April-July for colonoscopy and FS (2007/08 to 2013/14)



(source: DM01 NHS England)

- 4.92. The 2011 forecast considered five separate aspects of growth: underlying growth in diagnostic and therapeutic endoscopic activity; the age extension to the Faecal Occult Blood (FOB) testing screening programme; the introduction of the BSS programme; the growth in surveillance recall in the FOB testing screening programme; and additional demands, including the *Be Clear On Cancer* campaigns and GP direct access diagnostic investigations. This forecast has been updated with data up to March 2013. This is shown in Figure 4.2:

Figure 4.2 The actual and forecasted total lower GI activity updated to March 2013



(source NHS Analytical Services)

- 4.93. The actual (solid lines) and forecasted (dotted lines) show total lower GI endoscopic activity updated to March 2013. The update is shown between the red and blue vertical lines. The large increase in growth from 2013 is mainly driven by the introduction of the of the BSS screening programme.
- 4.94. Figure 4.2 shows that the growth in total activity up to the end of March 2013 was largely in line with the 2011 forecast, with the FOBT screening activity growth looking consistent with the 2011 modelling which underpinned the 2011 forecast. However, the main difference between the predicted and actual volume at March 2013 seems to come from growth that was assumed would be generated by increasing GP direct access to diagnostics as outlined in IOSC, which does not seem to have materialised as was originally anticipated. Likewise, the BSS programme was delayed due to IT issues, with 2,300 procedures by the end March 2013 compared to the anticipated 120,000 by March 2014. However, as previously reported, the BSS programme is now on track for full national roll-out by December 2016, with 325,000 procedures a year expected by 2016/17.
- 4.95. In addition to these figures on the number of procedures, analysis by NHS England in Figure 4.3 and Figure 4.4 shows considerable variation across CCGs in patients waiting for over 6 weeks for an endoscopy procedure, from 0 to 35%.

Figure 4.3 Distribution of the % of 6 week waits for colonoscopy by CCG

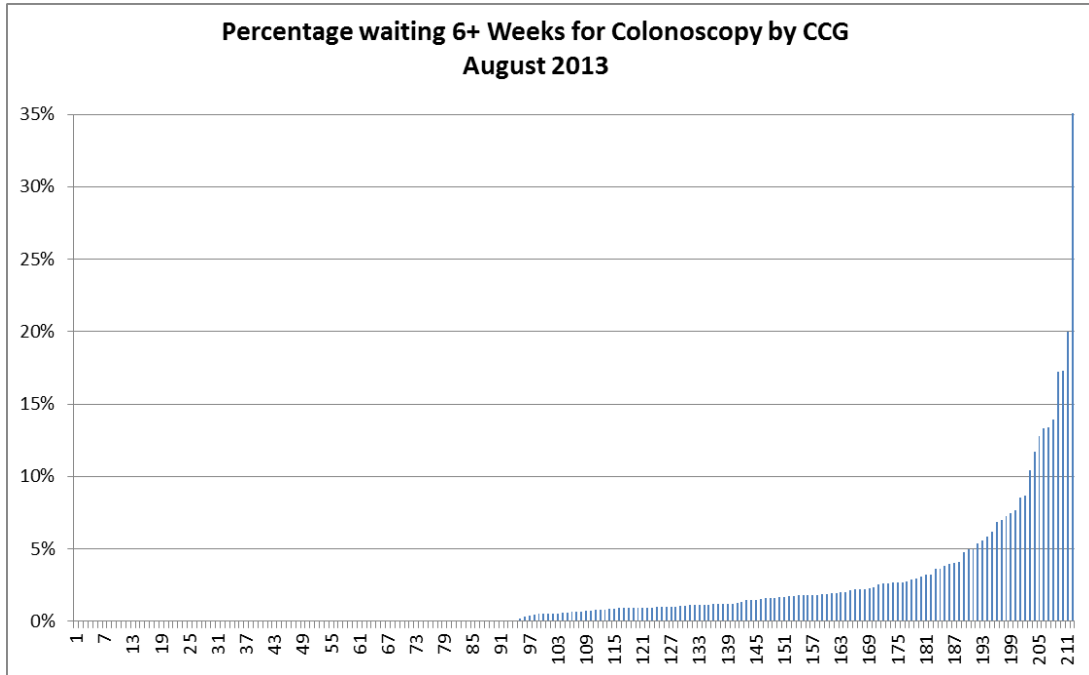
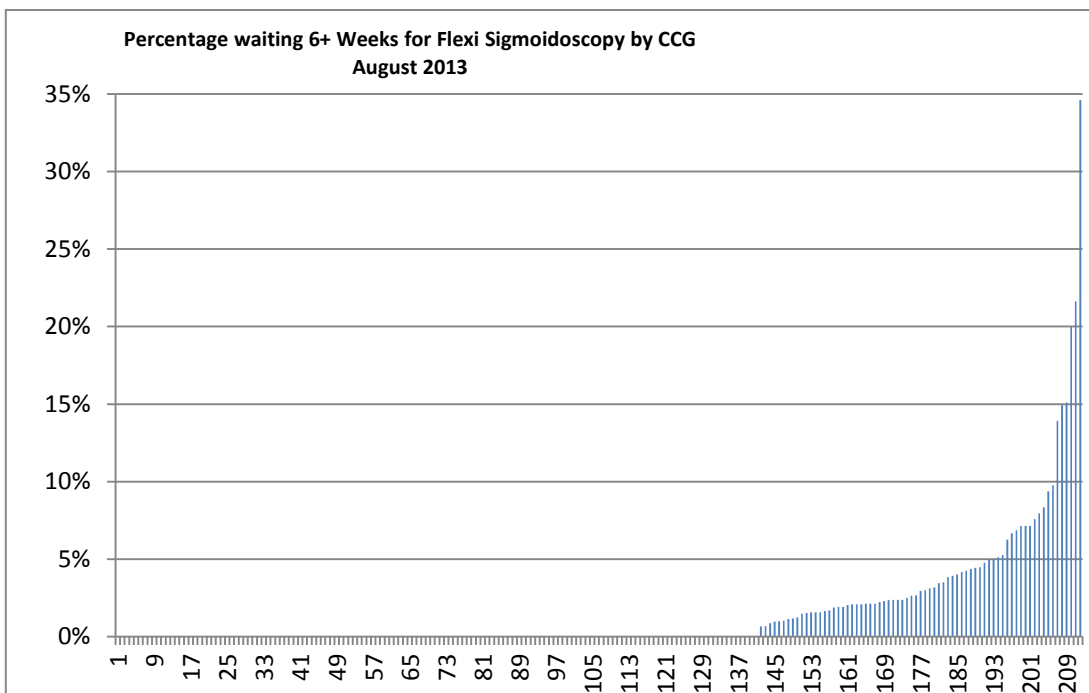


Figure 4.4 Distribution of the % of 6 week waits for flexible sigmoidoscopy by CCG



4.96. To help tackle the challenge of endoscopy capacity, NHS IQ has been progressing the endoscopy programme since April 2013. The resulting prototype *Productive Endoscopy* series is currently being tested over a six month period, with a full launch planned for January 2014. Productive Endoscopy is:

- Based on The Productive Theatre series
- Linking with the GRS Standards (endorsed by JAG)

- Using the NHS Change Model to ensure we understand enough to apply the principles of improvement – an evidence based, systematic application of change management approaches and application of ‘Lean’ methodology.
- 4.97. Nine sites have been identified as part of the testing phase, along with three new modules: referral management; pre-assessment and patient preparation; and patient experience and engagement toolkit.
- 4.98. As part of another NHS IQ work programme on acute upper gastro-intestinal bleeds, a questionnaire was sent to all trusts in England that offer an endoscopy service and had a 97% response rate. Additional questions were asked about workforce. The data from this questionnaire has provided insight into the way teams are structured, who is doing endoscopy across the country and the number of sessions different team members are doing to get a truer picture of the capacity available in the system as it currently stands. This will provide an excellent baseline from which to measure improvement in endoscopy across England. It also gives information about who currently offers lists on Saturdays and Sundays, as well sites who intend to in the next 12 months.
- 4.99. In order to help tackle the future challenge of endoscopy provision further, NHS England, PHE and Health Education England are working together to ensure that there is sufficient workforce to deliver the required endoscopy activity. This includes identifying the additional staffing numbers needed and ensuring that funding and appropriate training arrangements are in place to deliver them.

5. Treatment

Introduction

5.1. To improve cancer outcomes, it is essential that all cancer patients receive the best treatments available to the highest quality standards. Huge improvements have been made in treating cancer over the last few decades, but we want to improve treatment further. This chapter reports on progress with major radiotherapy commitments, including the Radiotherapy Innovation Fund and Proton Beam Therapy, and the success of the Cancer Drugs Fund. We also report on the growth of the Enhanced Recovery Programmes, and the continued importance of cancer peer review in driving up standards and improving outcomes.

Cancer waiting times

- 5.2. Speedy diagnosis and treatment of cancer is an important factor in improving outcomes. The latest quarterly National Statistics on waiting times for suspected and diagnosed cancer patients accessing NHS services⁴¹, produced by NHS England, were released on 4th December 2013 according to the arrangements approved by the UK Statistics Authority.
- 5.3. National performance against the cancer waiting times measures has been sustained. Table 4.1 shows both the level of achievement for Quarter Two (July to September 2013), the latest available figures, and the levels the NHS is expected to meet (the operational standards). The operational standards make allowances for the 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 4.1 Cancer Waiting Times, July to September 2013

Waiting Time Measure	Operational Standard	Quarter Two 2013-14 Achievement
All cancer two week wait	93%	95.2%
Two week wait for breast symptoms (where cancer was not initially suspected)	93%	94.5%
Two month (62 day) urgent GP referral to first treatment wait for all cancers	85%	86.7%

⁴¹ <http://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>

Waiting Time Measure	Operational Standard	Quarter Two 2013-14 Achievement
62 day wait for first treatment following referral from an NHS cancer screening service	90%	94.9%
62 day wait for first treatment following a consultants decision to upgrade the priority of the patient	None set; this has been left for local implementation.	92.0%
One month (31 day) diagnosis to first treatment wait for all cancers	96%	98.4%
31 day wait for second or subsequent treatment – surgery	94%	97.6%
31 day wait for second or subsequent treatment – anti-cancer drug regimens	98%	99.8%
31 day wait for second or subsequent treatment – radiotherapy	94%	98.0%

Source: DH waiting times for suspected and diagnosed cancer patients, provider based

Surgery

Enhanced Recovery Programme

- 5.4. Enhanced Recovery (ER) as a model of care delivery is continuing to spread across the England. It has been recognised as best practice and supported by the professional bodies to become the norm across surgical specialities and embedded into everyday clinical practice. ER has benefits of improving patient experience, patient safety and patient outcomes as well as the potential efficiency gains that can be realised locally.
- 5.5. The starting point for a good quality ER pathway should be the five Ps:
- Primary care ‘fitness for referral’ for common conditions
 - Patient Involvement: Shared decision making
 - Rehabilitation, assessment and care planning
 - Pain relief, fluid management, anaesthetics
 - Preparation for and effective discharge.
- 5.6. ER’s ability to reduce length of stay without increase in readmissions provides real efficiency benefits for the NHS. Good progress continues to be made in reducing length of stay across the following procedures: cystectomy; prostatectomy; colectomy; rectal surgery; abdominal surgery; and vaginal hysterectomy. There is growing evidence of spread of ER principles beyond the original specialties to both elective and non-elective surgical procedures. These include: thoracic surgery; hepato-biliary surgery; upper gastro-intestinal surgery; and emergency procedures.

- 5.7. Proactive management to help patients get better quicker has resulted in a reduction in length of stay. Despite rises in activity for almost all of these procedures, there were nearly 170,000 fewer bed days for these procedures in 2011/12 than in 2008/09. It has been estimated that further implementation of ER could save up to 20,000 additional bed days per year. Admission on the day of surgery continues to increase. In addition, the level of patients' experience reported in trusts who are implementing ER is higher than that reported nationally, as demonstrated in the national inpatient survey.
- 5.8. Regular benchmarking data on ER measures and a national enhanced recovery toolkit for local audit of ER implementation continues to be available to the NHS. The ER toolkit enables organisations to benchmark metrics such as: length of stay; day of surgery admission rates; compliance with 19 elements of ER; and readmission rates for procedures against the rest of the country.
- 5.9. The future challenge for ER is to:
- Ensure that all patients get the same standards of clinical care seven days a week
 - Increase patient engagement to help patients take control of their own acute pathway
 - Develop systems to optimise patients fitness for referral and pre-hospital risk stratification to improve patient safety
 - Developing internationally comparable outcome measures to further build on the evidence base.
- 5.10. The current national focus on delivering quality clinical pathways seven days a week, integrated across the whole system, and the Royal Colleges commitment to drive the delivery of ER as standard practice, support the future level of ambition, to extend the principles of ER beyond elective care and to ensure that all patients get the same standards of clinical care seven days a week.

National Lung Cancer Audit

- 5.11. The National Lung Cancer Audit provides an excellent example of how improvements in access to surgery are helping cancer patients. The *National Lung Cancer Audit 2013: Report for the audit period 2012*⁴² was published on 4th December 2013. The report showed that more than one in five patients with a group of common lung cancers underwent surgery in 2012, compared to one in seven in 2008. Just over 50% of the 40,200 lung cancer patients in England and Wales covered by the audit had non-small cell lung cancer, for which surgery offers the best chance of a cure when caught early enough. Among these, 22% had surgery as part of their treatment compared to 14% in 2008.

⁴² *National Lung Cancer Audit 2013: Report for the audit period 2012*, Health and Social Care Information Centre (December 2013)

<https://catalogue.ic.nhs.uk/publications/clinical/lung/nati-clin-audi-supp-prog-lung-canc-coho-2012/clin-audi-supp-prog-lung-nlca-2013-rep.pdf>

- 5.12. The audit also showed that the median average time that lung cancer patients survive from the date they are first seen in secondary care increased by 16% over five years to 221 days, compared to 191 days in 2008. 55% of patient survived for six months and 39% survived a year.

Radiotherapy

Radiotherapy levers for change

- 5.13. The radiotherapy (RT) specification for NHS England was implemented on 1st October 2013. The RT quality dashboard has been refined, is electronically populated and uploaded through the existing national RT dataset from October 2013.
- 5.14. The RT Innovation Fund of £23m was distributed to 50 centres, and an evaluation of how it was spent was published jointly by Cancer Research UK (CRUK), the Royal College of Radiologists, The College of Radiographers and the Institute of Physics and Engineering in Medicine in July 2013.⁴³ As a result, there has been a dramatic rise in Intensity Modulated Radiotherapy (IMRT) activity over the past 12 months with a doubling of the average from 13.6% to 27%. A few centres are failing to meet this level of activity and are currently being supported in developing plans to achieve the 24% threshold.
- 5.15. The Commissioning for Quality and Innovation (CQUIN) for RT for 2012/13 was IMRT, with a commitment that patients should have equitable access to innovative RT. This was in part defined as at least 24% of all radical RT patients receiving inverse planned IMRT.
- 5.16. The CQUIN for 2013/14 will be directed towards expanding Image Guided Radiotherapy (IGRT) activity. All IMRT should be complemented and verified by at least level two IGRT. Current IGRT activity is being surveyed and a targeted action plan will be developed to support training needs, replacement of outdated equipment and full implementation.
- 5.17. NHS England recognise the positive clinical impact that Stereotactic Ablative Body Radiotherapy (SABR) has made in the commissioned treatment of early non-small cell lung cancer, and will examine its potential utility in patients with oligometastatic disease.
- 5.18. NHS England's ambition is to adopt innovative RT technology, and this was facilitated by a meeting with manufacturers on 8th October 2013.

Proton Beam Therapy

- 5.19. High Energy Proton Beam Therapy (PBT) is a specialised form of radiotherapy that can improve outcomes for specific groups of patients. These include rarer cancers such as those occurring in children, young adults and some adult cancers, particularly sarcomas of the base of skull and spine regions.

⁴³ The Radiotherapy Innovation Fund: An evaluation of the Prime Minister's £23 million Fund (July 2013)

http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/rifevalreport.pdf

- 5.20. Highly selected patients suitable for PBT abroad currently travel to the USA for treatment at specialist centres in Jacksonville and Oklahoma. Support is provided for travel and accommodation and access is through a 'virtual' national expert clinical reference panel. Of the 502 patients referred for consideration for treatment since the programme started in 2008, 370 have been approved for treatment, of which 258 are children. An essential part of the overseas programme is the collection of clinical outcome data.
- 5.21. Treasury approval of the Outline Business Cases for the two confirmed English centres (at the Christie in Manchester, and University College London Hospitals, London) has been given (August 2013). It is being funded and overseen by the Department of Health (£250m capital programme). The procurement process for the equipment has been launched with the buildings to follow.
- 5.22. The clinical commissioning policies for PBT are within NHS England's routine advice and governance processes for directly commissioned specialised services. These will be further developed in line with emerging research and best practice, to ensure appropriate clinical indications are identified and will support the transition from the current overseas programme (around 150 cases in year) to the future England programme (up to 1500 cases per year) that will start in 2018.
- 5.23. A future programme of clinical work has been identified to ensure that a National Proton Beam Service develops streamlined referral pathways for patients through local MDTs and integrates care with specialised surgery and existing multidisciplinary treatment. Although this is a small proportion of all radiotherapy activity (1%), work is being undertaken to assess and manage the impact on workforce and existing service configurations.

Selective Internal Radiotherapy

- 5.24. Selective Internal Radiotherapy (SIRT) is an innovative form of radiotherapy involving the insertion of radioactive beads directly into the blood vessels supplying cancerous tumours in the liver. This enables a more precise dose of radiotherapy to the tumour, offering more protection to surrounding healthy liver tissues.
- 5.25. From November 2013, SIRT therapy became available to patients in England as part of a new evaluation programme, being launched by NHS England to help determine whether treatments showing significant promise might be routinely commissioned by the NHS in the future.
- 5.26. NHS England expect around 220 patients a year to be treated with SIRT under the *Commissioning through Evaluation* programme.

Chemotherapy

- 5.27. From April 2013, chemotherapy services have been directly commissioned by NHS England. The Chemotherapy service specifications for NHS England were implemented on 1st October 2013. A key requirement of these specifications is that all providers of chemotherapy services have in place an electronic prescribing system. Providers that

are not currently meeting this requirement have been required to agree action plans with NHS England to address this.

- 5.28. NHS England's Chemotherapy Clinical Reference Group formed in April 2013 and provides expert clinical advice to inform the commissioning of chemotherapy services. The group is working on the following areas to improve outcomes in chemotherapy services:
- Defining systemic therapy algorithms, initially for the commoner cancers but subsequently for all malignancies
 - Establishing e-prescribing for chemotherapy everywhere (rather than the 55% at present)
 - Instituting of acute oncology teams to ensure the rapid identification, treatment and discharge of patients suffering the side-effects of chemotherapy presenting to acute hospital services
 - Minimising variation in practice, partly by algorithms but by data-driven presentation of outputs from the Systemic Anti-Cancer Therapy (SACT) database (see Chapter 3)
 - Management of the Cancer Drug Fund to deliver the greatest degree of clinical value to cancer patients
 - Partnerships with pharmaceutical companies on the early introduction of innovative drugs with planned data collections to aid assessment of value in everyday practice to patients and NHS England
 - Efficiency savings in terms of setting delivery tariffs, for example encouraging trusts to set up home delivery of chemotherapy
 - Inputting to the establishment of a framework for the delivery of appropriate molecular diagnostics.
- 5.29. The NHS England Patient Safety Team continues work to implement the use of non-Luer Spinal devices for intrathecal chemotherapy to further minimise the risk of wrong route errors. This is where intravenous chemotherapy has been administered by the intrathecal route in error. There have not been any incidents since 2001, but use of new devices will further minimise this risk. A Patient Safety Alert was issued for stakeholder engagement in November 2013.

Cancer Drugs Fund

- 5.30. The Government established the Cancer Drugs Fund from 1 April 2011 to help patients get the additional cancer drugs their doctors recommended. The Fund would provide £200m a year for three years and built on £50 million of additional in-year funding that was allocated to the NHS to support improved access to cancer drugs in 2010/11.
- 5.31. Since October 2010, this funding has helped over 38,000 cancer patients in England to access the additional cancer drugs their doctors think they need.
- 5.32. The Government announced in September 2013 that a further £400 million will be made available to extend the Fund to the end of March 2016.

Genomics

- 5.33. The Prime Minister's initiative to sequence 100,000 whole genomes will help keep the UK in the forefront of the genomics revolution worldwide, with whole genome sequencing linked to patient diagnosis, treatment and care - leading the global race for better tests, better drugs and above all better, more personalised care. £100million in funding has been made available for the initiative, including sequencing, training, and analysing the data securely. The Department of Health has established Genomics England, to deliver whole genome sequencing capacity and data storage to support the NHS and UK researchers in adopting genomic technologies.
- 5.34. The CRUK Stratified Medicine Programme has demonstrated the feasibility of rolling out molecular diagnostics within the NHS, through a pilot programme involving 9,000 patients across 21 hospitals and six tumour types. The programmes completed in June 2013.

Peer Review

- 5.35. In 2012/13, the National Cancer Peer Review (NCPR) programme completed its fourth annual round of peer review using the current methodology, with the Chief Executive of the service provider endorsing reports supported by external verification and risk-based peer review visits. The work to ensure sustainability of the programme continues and services that demonstrated previous high performance have received less external assessment but maintained their internal governance.
- 5.36. The quality of cancer services in England as a whole continues to improve. Services which have been part of the peer review process for a longer period have in general performed better and this indicates that a culture of quality assurance is becoming embedded. However, where services are new to the process, further work is required.
- 5.37. Significantly more patients and carers have accessed the peer review reports and Macmillan Cancer Support is now working in partnership with the programme to further development *My Cancer Treatment*⁴⁴, a web tool enabling patients to have easy access to peer review reports. The site has had 23,445 hits since its launch in December 2012.
- 5.38. NCPR has developed stronger links with the National Cancer Intelligence Network (NCIN), using outcomes data from existing service profiles where they exist, or developing clinical indicators where they do not, for Clinical Lines of Enquiry. NCPR has also routinely used the findings of the national Cancer Patient Experience Survey (CPES) as a key indicator for the quality of the service. The programme continues to strive to move towards a more clinical and patient outcomes focus rather than being reliant on structure and function alone.
- 5.39. The NCPR now looks at the findings on the quality of cancer services for 1,241 tumour multi-disciplinary teams (MDTYs) and 277 network site specific groups (NSSGs), along with services for acute oncology, chemotherapy, radiotherapy, children, teenagers and young adults cancers, cancer research networks, rehabilitation, complementary therapy,

⁴⁴ <http://www.mycancertreatment.nhs.uk/>

network partnership groups and network psychological support groups. The programme now reviews the quality of 1,842 clinical cancer services/teams.

- 5.40. The national overview shows that some teams and services continue to achieve very high levels of compliance with the measures. When considering all of the MDTs and NSSGs, 745 (49%) achieved compliance with over 90% of the measures. In relation to cross-cutting services, 166 radiotherapy services, 323 chemotherapy services and 37 acute oncology services achieved compliance with over 90% of the measures. In children, teenagers and young adults services, 169 achieved compliance with over 90% of the measures.
- 5.41. However, the 2012/2013 round of peer review has again highlighted some significant challenges. There is a group of significant outliers, and work needs to be done to address these services. This is a particular concern in relation to acute oncology and neuroscience where some services have not yet been appropriately established. In light of *The final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*⁴⁵ (the Francis report, February 2013), the *Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report*⁴⁶ (the Keogh review, July 2013) and the National Advisory Group on the Safety of Patients in England's report *A promise to learn – a commitment to act: Improving the Safety of Patients in England*⁴⁷ (August 2013), it is important we work together in the NHS as clinicians, managers and commissioners to address these services. Some of these will have already been addressed at a local level following the relevant visits and report. Others need to be addressed as soon as possible. In some cases, compliance could be improved through local effort, but 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 need to be merged to achieve sustainability both of workforce and throughput of patients.
- 5.42. NCPR continues to work with the Care Quality Commission (CQC), and the new Chief Inspector of Hospitals is supportive of the programme and recognises its potential value in supporting his hospital inspection model. NCPR will continue to support commissioners and it is planned to formalise arrangements with NHS England's Clinical Director for Specialised Commissioning to provide information on the implementation of service specifications and to inform the work of the Clinical Reference Groups.

Work on older people

POI/NCEI project

- 5.43. Previous work by the NCEI and the NCIN has identified that cancer treatment rates decline with age. To a certain extent this is to be expected. Cancer treatment is often invasive or associated with significant side effects. As a result of frailty or co-

⁴⁵ <http://www.midstaffpublicinquiry.com/report>

⁴⁶ <http://www.nhs.uk/NHSEngland/bruce-keogh-review/Documents/outcomes/keogh-review-final-report.pdf>

⁴⁷ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

morbidities, older people may be less well-equipped to cope with intensive treatment. Yet more intense treatment is often associated with better and longer term clinical outcomes. It is therefore important that we do all that we can to ensure that treatment is tailored to a patient's preferences, personal circumstances and wider health. Chronological age alone should not be used as a proxy for other factors.

- 5.44. In order to investigate further patterns of treatment for older people in the NHS, the NCEI has worked in partnership with the NCIN and the Pharmaceutical Oncology Initiative (POI) to conduct the first ever comprehensive analysis of the use of chemotherapy for breast, colorectal and lung cancer in England in the context of age and performance status of the patient. The report utilises data from the SACT data set, with analysis based on nearly 63,000 course of chemotherapy.
- 5.45. The analysis, published in *Are older people receiving cancer drugs? An analysis of patterns in cancer drug delivery according to the age of patient* (December 2013, available on the NHS England website: www.england.nhs.uk/), shows that the proportion of patients given chemotherapy declines rapidly from the age of 70 for breast, colorectal and lung cancer, when compared with the overall burden of illness in those age groups.
- 5.46. There also appears to be a decline in the proportion of older patients who are given chemotherapy with a curative intent, i.e. as part of treatment for early stage cancer. This may be because of alternative treatment options, patient choice or expectation, or because clinicians believe that the harms of such treatment could outweigh the benefits.
- 5.47. Variation in the age profile of chemotherapy patients also occurs at provider level. It does not seem plausible that differences in referral patterns or the age profile of populations served by hospitals could explain these variations alone.
- 5.48. It is important to stress that there is no correct level of chemotherapy treatment in older people and there may well be good reasons for declines in chemotherapy rates, including patient preference and, in some cases, alternative forms of treatment. The variations identified require further exploration and, at this stage, it is important that no conclusions should be drawn about the quality and appropriateness of treatment given to older patients at different providers.
- 5.49. It is best practice that cancer services constantly assess whether they are delivering the best possible treatment and care to the population they serve, especially the needs of older people in an ageing population. The report identifies a range of actions that different organisations may wish to consider in playing their part in ensuring older patients are offered appropriate treatment.

Making sure older people have access to appropriate interventions

- 5.50. The *Cancer Services Coming of Age* report⁴⁸ summarises a series of pilots that tested whether appropriate assessment of older cancer patients would result in improved

⁴⁸ *Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project*, Department of Health/Macmillan Cancer Support/Age UK (December 2012)

access to appropriate cancer treatment, based on need and not age. They also tested whether action, as a result of an age appropriate assessment, improved the scope for older people to benefit from treatment.

- 5.51. Cancer services face three key challenges in relation to older people over the coming years, including:
- Improving survival rates in the population aged 75 years and over
 - To deliver high quality services to increasing numbers of older patients with cancer, including age appropriate assessment, for example the Comprehensive Geriatric Assessment (CGA)
 - The involvement of elderly care specialists.
- 5.52. Pilots have demonstrated that using the CGA and involving elderly care specialists make a significant difference to older patients in making decisions about treatment and not having those decisions made for them, based on assumptions on their willingness to undergo treatment and their tolerance to it.
- 5.53. The report emphasises the importance of abiding by the Equality Act 2010, now extended to public services in 2012, to ensure that there is no direct or indirect discrimination in the delivery of health services to older people with cancer. It makes six recommendations to services, which may assist better provision for all cancer patients if holistic, tailored assessment, treatment and advice is delivered. The report is aimed at commissioners, commissioning support units and providers to help them understand how services may offer appropriate assessments and treatments to older cancer patients.

6. Patient experience and survivorship

Introduction

6.1. The Cancer Patient Experience Survey has been pivotal in highlighting variations reported by cancer patients and in highlighting areas where trusts can make improvements. This chapter reports on the results of the third annual survey, along with interesting results from the new radiotherapy and chemotherapy patient surveys. We also report on progress with the National Cancer Survivorship Initiative, which aims to improve the quality of life for the 1.8 million living with and beyond a cancer diagnosis in England, and improvements in end of life care.

Cancer Patient Experience Survey 2013

6.2. The third annual national Cancer Patient Experience Survey was published in August 2013⁴⁹ and reported the views of over 116,000 cancer patients in all 155 NHS trusts in England that provide treatment to cancer patients. The survey showed improvements in many areas since last year and very positive experience of aspects of care such as privacy, being treated with respect, being listened to and being given good information. Improvements in the scores are being seen with each survey, indicating that the trusts individually and the NHS collectively is listening, clearly demonstrating the power of the patient voice.

6.3. However, the scores of 31 trusts have deteriorated since last year and although these falls were marginal, it shows there is more work to do. Some of the areas for concern reported nationally were around care planning, information about financial support and relational care (eg what names patients preferred to be called). In addition, some equality groups continue to report a poorer experience. These include: black and minority ethnic (BME) groups; younger people; lesbian, gay, bisexual and transgender people; and women. Patients attending London hospitals also continue to be less positive about their care than any other region of England. There was no discernible difference in the scores reported for the questions relating to research.

6.4. In September 2013, Macmillan Cancer Support published *Cancer Patient Experience Survey: Insight Report and League Table 2012/13*⁵⁰, which highlighted the 10 most improved trusts between the 2011/12 and 2012/13 surveys. This is shown in Table 5.1.

⁴⁹ <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file>

⁵⁰ <http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/2013CPESInsightBriefingFINAL.pdf>

Table 6.1 Top 10 improved NHS trusts, ranked by the number of scores showing significant improvements between 2011-12 and 2012-13

Rank	Trust	Number of scores improving
1	University Hospital Southampton NHS Trust	18
2	Royal Cornwall Hospitals NHS Trust	17
3	The Royal Wolverhampton NHS Trust	15
4	Nottingham University Hospitals NHS Trust	13
5	Oxford University Hospitals NHS Trust	12
6	Worcestershire Acute Hospitals NHS Trust	11
7	Royal Devon and Exeter NHS Foundation Trust	10
8	East Kent Hospitals NHS Foundation Trust	10
9	Basildon and Thurrock University Hospitals NHS Foundation Trust	9
10	Derby Hospitals NHS Foundation Trust	8

6.5. The Macmillan report also highlighted the top 10 and bottom 10 trusts in the survey, as shown in Table 5.2 and Table 5.3.

Table 6.2 Top 10 performing trusts, ranked by the number of times they appear in the top 20% of responses to a specific question in the 2013 CPES

Rank	Trust	Times in top 20%
1	Gateshead Heath NHS Foundation Trust	44
2	East Cheshire NHS Trust	43
3	South Tyneside NHS Foundation Trust	41
4	The Rotherham NHS Foundation Trust	41
5	Liverpool Women's Hospital NHS Foundation Trust	39
6	Chesterfield Royal Hospital NHS Foundation Trust	38
7	St Helens and Knowsley Teaching Hospitals NHS Trust	36
8	Bolton NHS Foundation Trust	35
9	Papworth Hospital NHS Foundation Trust	35
10	Northumbria Healthcare NHS Foundation Trust	34

Table 6.3 Bottom 10 performing trusts, ranked by the number of times they appear in the bottom 20% of responses to a specific question in the 2013 CPES

Rank	Trust	Times in bottom 20%
1	Imperial College Healthcare NHS Trust	55
2	Barts Health NHS Trust	50
3	Croydon Health Services NHS Trust	43
4	Barking, Havering and Redbridge University Hospitals NHS Trust	42
5	King's College Hospital NHS Foundation Trust	41
6	North Middlesex University Hospital Trust	39
7	St George's Healthcare NHS Trust	39
8	Whittington Health	37
9	The North West London Hospitals NHS Trust	36
10	The Dudley Group NHS Foundation Trust	33

- 6.6. NHS England has committed to run CPES again in 2014 for patients treated between September and November 2013.
- 6.7. In addition to the main survey, two additional modules on patients receiving radiotherapy and chemotherapy were published in 2013 (see below). This was the first time patients receiving these specific treatments had been asked their views about their care in a national survey. The reports will be used by the respective Clinical Reference Groups within Specialised Commissioning and their provider organisations to drive up quality improvements in these areas.
- 6.8. NHS Improving Quality (NHS IQ) will be doing a suite of work across all surveys to understand what the barriers are to implementing change and to showcase best practice where real improvements can be demonstrated.

Radiotherapy Patient Experience Survey

- 6.9. The Radiotherapy Patient Experience Survey was undertaken on behalf of DH and the National Cancer Action Team in early 2013 in all 50 trusts in England who undertake radiotherapy work. Of the final sample of 34,232 patients, 24,101 completed and returned a questionnaire, a response rate of 70%.
- 6.10. The findings of the survey were broadly positive, for example:
- 96% of patients said they were told very clearly how many treatments they would probably need
 - 94% of patients rated their care as excellent or very good
 - 94% of patients said they were given information on radiotherapy before treatment started
 - 90% of patients said their treatment plan was explained very clearly to them by a

member of staff

- 87% of patients said they had been given a helpline number to call if they had a problem with their treatment.

6.11. However, there were a number of issues on which patients rated the radiotherapy service they received as less positive, for example:

- 29% of patients said they understood the benefits of radiotherapy and its side effects only to some extent or not at all
- Only 30% of patients had looked for information on radiotherapy on a charity website
- Only 21% of patients had accessed information about radiotherapy from the website of the hospital or centre where they were being treated
- Only 67% of patients reported their treatment starting on time or within 20 minutes of the expected time
- Only 68% of patients reported being told about the existence of the local support service.

6.12. Interestingly, unlike the main CPES, there were less pronounced differences between different groups. Regional differences were less pronounced, as were differences between BME patients and white patients and between non-heterosexuals and heterosexuals. However, differences between patients who had radiotherapy whilst they were inpatients and those who had radiotherapy in a day case/outpatient setting were much more significant than in the main CPES, with inpatients reporting a less positive experience.

Work to improve patient experience

6.13. NHS Improving Quality will be working with the National Clinical Director for Cancer and with provider organisations to continue their service improvement work to improve patient experience and to ensure that patients' views are central to the way services are developed.

6.14. Work on information prescriptions (IPs) has moved to Macmillan Cancer Support, and a report on the use of IPs is currently being considered by NHS England to decide how best this work can be taken forward. Work on quality in nursing was completed in March 2013, with the clinical nurse specialist survey handed over to Macmillan Cancer Support. NHS England is considering how to take forward work on the *Multi-disciplinary team – feedback for improving team working* (MDT-FIT) programme.

6.15. The *Connected* national advanced communication skills training programme trained approximately 17,000 clinicians in the five years from 2008-2013. The vast majority of these were from the MDTs and many of the delegates work in wider clinical areas. During the transition, arrangements were made with several providers to continue delivery of the course and details can be found on the on-line booking system:

<https://www.connectedonlinebookings.co.uk>

National BME Cancer Voice

6.16. The Black Health Initiative (BHI) took over the co-ordination of BME Cancer Voice in October 2013. BHI is a community engagement organisation, working with disadvantaged and marginalised communities towards equality of access to education, health and social care within the Yorkshire region. BHI do this in partnership with local authorities, national charities and the communities themselves. BME Cancer Voice has over 400 members, and provided useful and practical advice on how to improve the experience of BME patients, thus narrowing the inequalities gap. BHI will also publish the findings of the first in-depth survey looking at the information experiences of over 500 BME cancer patients.

The National Cancer Survivorship Initiative

6.17. Since 2007 the National Cancer Survivorship Initiative (NCSI) has set out to understand the numbers, needs, experiences, and most effective service solutions to meet the growing numbers of people living with and beyond cancer. Increasing incidence and better survival rates mean the number of cancer survivors will grow to 3.4 million by 2030.⁵¹

6.18. In March 2013 DH published the NCSI document *Living with and beyond cancer: taking action to improve outcomes*⁵², which describes five stages to a survivorship pathway and includes the evidence behind a number of tested solutions which improve outcomes and help to address the cost challenges of the NHS. The report outlines five steps to survivorship: information and support from point of diagnosis; promoting recovery; sustaining recovery; managing consequences of treatment; and supporting people with active and advanced disease. These steps are underpinned by improving survivorship intelligence.

6.19. In the report, the NCSI recommended four priority solutions: survivorship recovery package; stratified pathways of care; physical activity; and Patient Reported Outcomes Measures (PROMs). Boxes 1, 2, and 3 show examples of local activity.

Survivorship recovery package

6.20. The survivorship recovery package includes: assessment and care planning; treatment summary and cancer care review; and a health and wellbeing event. This package of support provides a personalised care plan, supports patients to self-manage and adopt healthier lifestyles, and reduces usage of hospital and primary care services. The package is 'roll-out ready'.

⁵¹ Macmillan Cancer Support estimates of prevalence at the end of 2010, 2020 and 2030 by nation calculated by applying prevalence rates per 100,000 population for the UK by age band from Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202. Population estimates for 2010, 2020 and 2030 from the Office for National Statistics. Estimates made by nation for the end of 2010, 2020 and 2030 assuming that the rates for the UK are consistent across each nation

⁵² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf

Box 1

London - In the *Transforming Cancer Services for London* programme, Clinical Commissioning Groups have placed within all 29 acute provider 2013/14 contracts requirement for the delivery of holistic needs assessments (HNAs), care plans and treatment summaries. It is anticipated that by March 2014 over 50% of people will have been offered a HNA and should have a care plan and a treatment summary. For 2014/15, London is working to implement Health and Well Being events in contracts, and increase take up of other elements, with a view to moving to 100% implementation in 2015/16.

Stratified pathways of care

- 6.21. *Stratified cancer pathways: redesigning services for those living with or beyond cancer*⁵³ was approved by NICE and published in October 2013 as a Quality and Productivity: Proven Case Study. The initiative focused on redesigning follow-up pathways for people with breast, colorectal and prostate cancer. This included the development of supported self-management pathways for those who have been treated with curative intent, whose treatment has been completed and in whom side effects of treatment have subsided.
- 6.22. Supporting patients to self-manage their own health and wellbeing can meet unmet needs and reduce demand on services, where appropriate. This can be done in the following ways:
- Stratifying patients to an appropriate pathway based on clinical and individual need
 - Organising needs assessments and care plan reviews at key points
 - Providing a treatment summary
 - Improving access to clinical and non-clinical support services
 - Offering advice on health and wellbeing, signposting to local support services
 - Ensuring surveillance tests continue to be scheduled and monitored by the specialist team.
- 6.23. 'Stratified' means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, the treatment and the person. The three forms of aftercare are: supported self-management; shared care; and complex case management.

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<https://www.evidence.nhs.uk/document?ci=http%3A%2F%2Farms.evidence.nhs.uk%2Fresources%2FQIPP%2F1029456&ReturnUrl=%2Fqipp%2Fwhats-new%2Fsearch%3Fs%3Ddate%26am%3D%5B%7B%2522srn%2522%3A%5B%2522%2520qipp%2520%2522%5D%7D%5D%26fs%3Dqippcat.WhatsNew>

Box 2

Hull and East Yorkshire - Hull and East Yorkshire Hospitals NHS Trust, supported by the North East Yorkshire and Humber Clinical Alliance, redesigned the gynaecological cancer patient pathway to incorporate the holistic needs assessment and to address the long-term consequences of cancer and treatment. The initiative has created a more efficient and cost-effective service, and enables patients to be referred to the most appropriate professionals to meet their needs. The work was highly commended in the Cancer Care category in the Nursing Times and Health Service Journal Care Integration Awards 2012.

Physical activity

6.24. Physically activity improves patient and carer wellbeing, improves survival by reducing the risk of cancer recurrence or other long-term conditions, and is cost-effective to deliver. The publication of *Walking Works: Making the case to encourage greater uptake of walking as a physical activity and recognise the value and benefits of Walking for Health*⁵⁴ in October 2013 by Walking for Health, a partnership between the Ramblers and Macmillan, gives an overview of research, and shows how England's largest network of health walk schemes is already changing people's lives. In March 2013 Sport England made a grant to Macmillan of £0.5m to improve the opportunities for sports for people who are living with cancer, and piloting work is underway.

PROMs and consequences of treatment

- 6.25. Patient Reported Outcome Measures (PROMs) provide evidence about the unmet needs and consequences of treatment of large cohorts of survivors. This evidence is essential to plan the provision of appropriate monitoring and support services, including specialist services for people with complex consequences of treatment. Publication of the follow-up survey of the 2011 PROMs respondents is expected soon, as are the results of the first national survey of people who have been diagnosed with colorectal cancer. A call out was issued in November 2013 from Prostate Cancer UK in regard to conducting a national PROM survey of those who have been diagnosed with prostate cancer.
- 6.26. PROMs can uncover specific issues affecting large number of people, such as the reduced quality of life due to urinary leakage or bowel difficulties, as shown in the first PROMs survey of cancer survivors from 2011⁵⁵, which indicated that many hundreds of

⁵⁴ http://www.walkingforhealth.org.uk/sites/default/files/Walking%20works_LONG_AW_Web.pdf

⁵⁵ *Quality of Life of Cancer Survivors in England. Report on a Pilot Survey Using Patient Reported Outcome Measures (PROMS)*, Department of Health, 2012:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213192/9284-TSO-2900701-PROMS.pdf

thousands of cancer patients in the UK are affected not only by the disease itself, but by the consequences of its treatments.

6.27. In Oct 2012 the patient guide *What to do after cancer treatment ends: 10 top tips*⁵⁶ was launched to alert patients of the issues that they may be facing and how they can help keep themselves healthy – some 25,000 copies have been distributed. In July 2013, *Throwing Light on the Consequences of Cancer and its Treatment*⁵⁷ brought together, for the first time, evidence on the prevalence of consequences of treatment which underpins calls to:

- Improve education and awareness for both professionals and patients
- Ensure professionals identify people at risk of consequences of treatment
- Support patients through local pathways for care of consequences of treatment, with referral to specialist services where needed.

Box 3

Royal Marsden - The Royal Marsden Hospital Gastrointestinal and Nutrition Service currently consists of a consultant gastroenterologist, a nurse consultant and a specialist dietician, and receives approximately 250 new referrals per year from across the UK. The team is actively engaged in research on the influencing factors, diagnostic tests and treatments for pelvic radiation disease. Results from its large randomised controlled trial (ORBIT) published in the *Lancet* in Sept 2013⁵⁸ show that their clinical algorithm can ameliorate radiotherapy-induced gastrointestinal symptoms.

Children and young people

6.28. For children and young people (CYP) survivorship services, the spread and implementation phase to paediatric centres was completed from a national perspective in June 2013, and the learning and recommendations shared with local teams to continue any further implementation of the aftercare pathways.

6.29. For CYP services transition into adult services, NHS Improving Quality (NHS IQ) will define the key components and outcomes measures to provide the basis of a generic service specification by March 2014, working with commissioners at a local and national level. Future work on transition services may include developing Children and Adolescent Mental Health Services and learning disability transition service specifications, and linking all parts of the transition service pathways from primary, secondary and tertiary care, working with Clinical Commissioning Groups to commission continuation of care with specialist clinical nurse support.

⁵⁶ <http://www.macmillan.org.uk/Documents/Cancerinfo/Livingwithandaftercancer/Whattodoaftertreatment.pdf>

⁵⁷ *Throwing light on the consequences of cancer and its treatment*, Macmillan Cancer Support, July 2013: www.macmillan.org.uk/throwinglight

⁵⁸ Andreyev HJN, Benton BE, Lalji A, et al. *Algorithm-based management of patients with gastrointestinal symptoms in patients after pelvic radiation treatment (ORBIT): a randomised controlled trial*. *Lancet* 2013. doi:10.1016/S0140-6736(13)61648-7

The future of the NCSI

6.30. We will continue to support the NCSI, with the Chief Executive of Macmillan Cancer Support and the National Clinical Director for Cancer in NHS England as co-chairs. There will be a revised governance structure to reflect the new system architecture, and a continued focus on strengthening the evidence and spreading learning and good practice through publications, conferences, and events. Given the synergies between cancer survivorship and other long-term conditions, NCSI will align with the work of other NHS England Domain teams (particularly Domain 2) and NHS IQ.

End of Life Care

6.31. The End of Life Care Strategy is now five years on and covers deaths for all conditions and in all 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

6.32. Progress continues to be measured through a Proxy Key Performance Indicator on improving the proportion of deaths in someone's usual place of residence (DiUPR). Latest data, for the period Quarter 3 2011 2012 to Quarter 2012-13 show continuing improvement quarter by quarter now standing at DiUPR 43.1% .

National VOICES of bereaved people

6.33. In July 2013, the Office of National Statistics published the second annual VOICES survey of bereaved relatives. This showed that:

- The overall quality of care across all services in the last three months of life was rated by 44% of respondents as outstanding or excellent
- Respondents of those who died of cancer in their own home rated the quality of care most highly (63%)
- Being shown dignity and respect by staff was highest in hospices (84% 'always' for hospice doctors and 82% for hospice nurses) and lowest in hospitals (59% 'always' for hospital doctors and 52% for hospital nurses)
- For those who expressed a preference, the majority preferred to die at home (81%), although only half of these actually died at home (49%). The most commonly reported place of death was a hospital (52%).

Electronic Palliative Care Coordination Systems

6.34. Work has continued to increase the uptake of electronic palliative care coordination systems (EPaCCS) improving the quality of care coordination and further supporting preferences for end of life care there is currently 30% coverage across CCGs and 60 % have plans in place for 2013/14 to support implementation.

Palliative Care Funding Review

6.35. 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.

- 6.36. Ministers selected and announced the seven adult and one children's pilot sites in March 2012. The pilots are all local partnerships. The pilot sites have made good progress and have published their interim findings for the first year. The sites will continue to collect data to March 2014. Ministers have requested that the new funding system be in place by 2015, a year sooner than the review proposed.

Liverpool Care Pathway

- 6.37. In January 2013 the Government commissioned an independent review of the Liverpool Care Pathway, in response to concerns raised about poor care experienced by patients and their families. The review published its findings on 15 July, including a range of recommendations for national organisations. A Leadership Alliance for the Care of Dying People (LACDP) has been set up under the chairmanship of Dr Bee Wee, National Clinical Director for End of Life Care at NHS England, to take forward the recommendations in the review.
- 6.38. The Government has accepted the review panel's recommendations that the Liverpool Care Pathway to be phased out over the next 6-12 months and that there should be an individual approach to end of life care, with a personalised care plan for each patient and a named senior clinician responsible for its implementation. The Government is working with the LACDP and other stakeholders across health and care to inform a full system-wide response to the review's recommendations before the end of 2013.

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

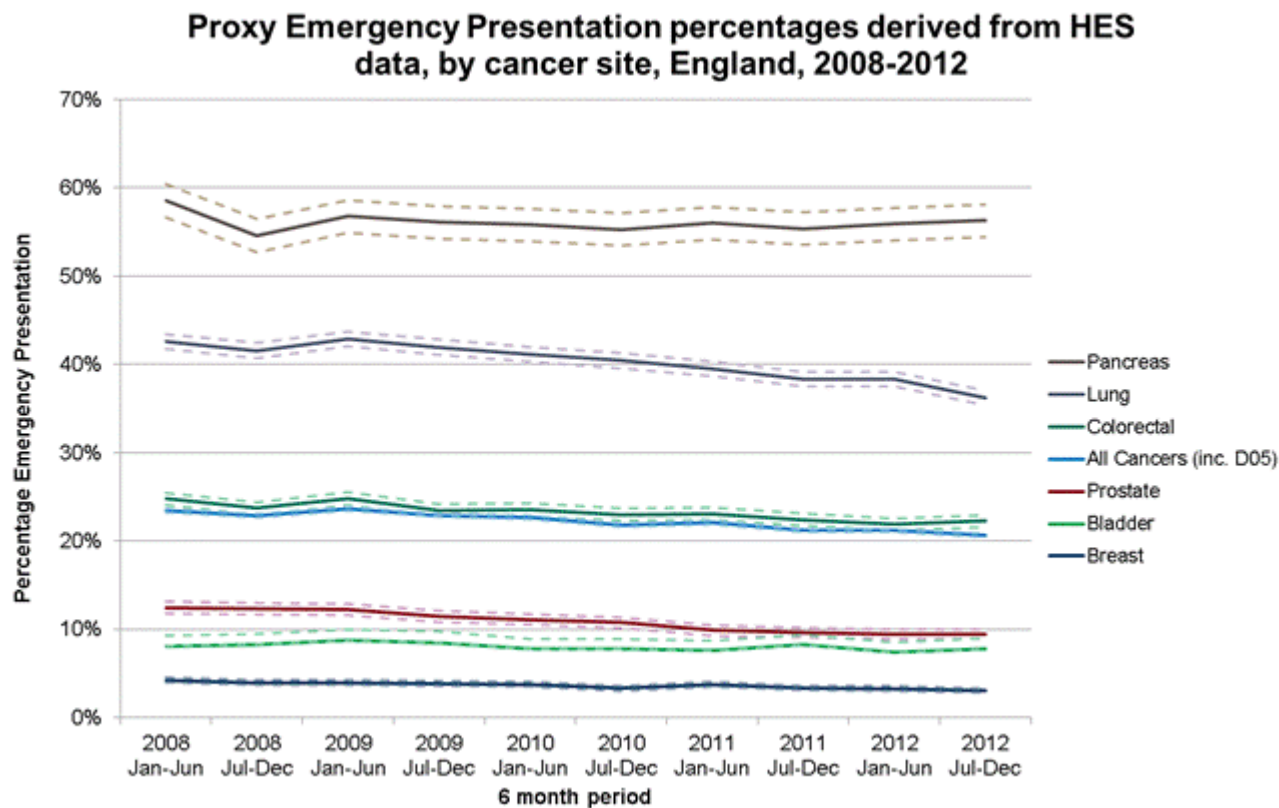
- 6.39. End of life care spans both health and social care. QIPP highlights this connection in its emphasis on providing good quality care where people want it, in the community, with the focus on productivity aiming to avoid unnecessary hospital stays. Both of these point to improving community-based 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."

- 6.40. 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.
- 6.41. 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.

Annexes

Annex A - Emergency presentations



Source: NCIN, Source of data: Hospital Episode Statistics, The Health and Social Care Information Centre. Copyright ©2013, re-used with the permission of the Health and Social Care Information Centre. All rights reserved

Annex B – Number of people living with and beyond cancer by time since diagnosis, sex and country of origin

Segmenting the cancer survivor population in England

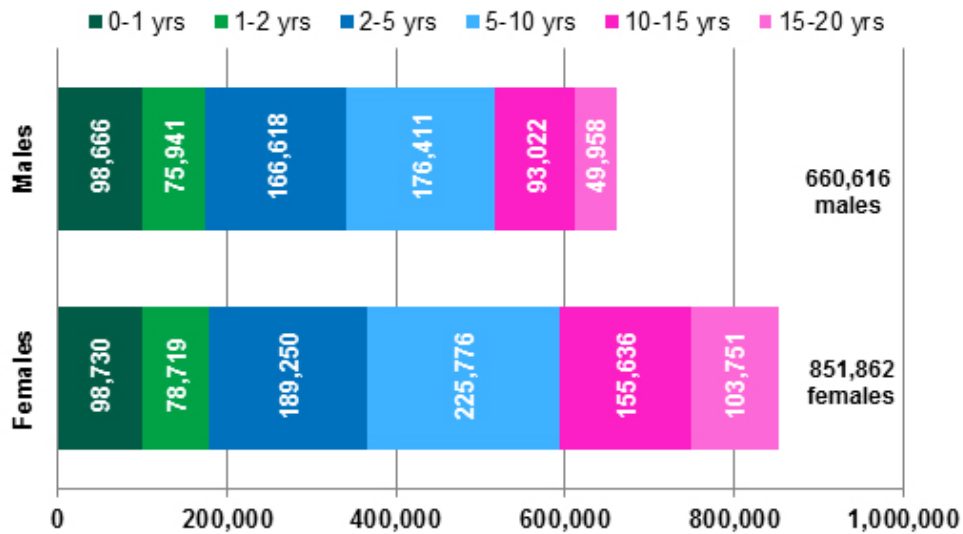
The Macmillan-NCIN partnership*

Twenty-year cancer prevalence based on people diagnosed with cancer in the period 1991-2010 and alive at the end of December 2010, for all malignant cancers combined (excluding non-melanoma skin cancer)

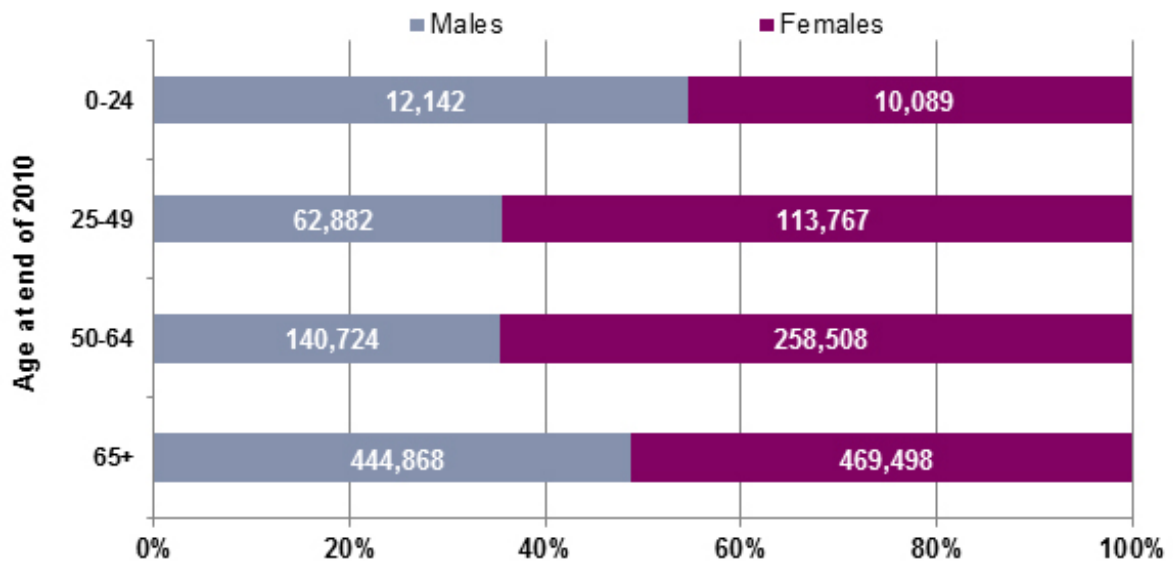
Number of people	Time since first cancer diagnosis						
	0-1 years	1-2 years	2-5 years	5-10 years	10-15 years	15-20 years	20 year total
Age at end of 2010							
0-24	2,678	2,295	5,186	5,749	3,779	2,544	22,231
25-49	24,214	20,398	45,498	45,698	26,156	14,685	176,649
50-64	56,234	44,499	99,350	103,507	61,321	34,321	399,232
65-69	28,784	22,300	49,459	53,445	30,845	18,953	203,786
70-74	27,035	21,277	51,555	57,549	33,514	20,111	211,041
75+	58,451	43,891	104,820	136,239	93,043	63,095	499,539
Total	197,396	154,660	355,868	402,187	248,658	153,709	1,512,478

% distribution by age group	Time since first cancer diagnosis						
	0-1 years	1-2 years	2-5 years	5-10 years	10-15 years	15-20 years	20 year total
Age at end of 2010							
0-24	12%	10%	23%	26%	17%	11%	100%
25-49	14%	12%	26%	26%	15%	8%	100%
50-64	14%	11%	25%	26%	15%	9%	100%
65-69	14%	11%	24%	26%	15%	9%	100%
70-74	13%	10%	24%	27%	16%	10%	100%
75+	12%	9%	21%	27%	19%	13%	100%
Total	13%	10%	24%	27%	16%	10%	100%

Twenty-year cancer prevalence based on people diagnosed with cancer in the period 1991-2010 and alive at the end of December 2010, for all malignant cancers combined (excluding non-melanoma skin cancer), by time since diagnosis and sex, England



Twenty-year cancer prevalence based on people diagnosed with cancer in the period 1991-2010 and alive at the end of December 2010, for all malignant cancers combined (excluding non-melanoma skin cancer), by sex and age, England

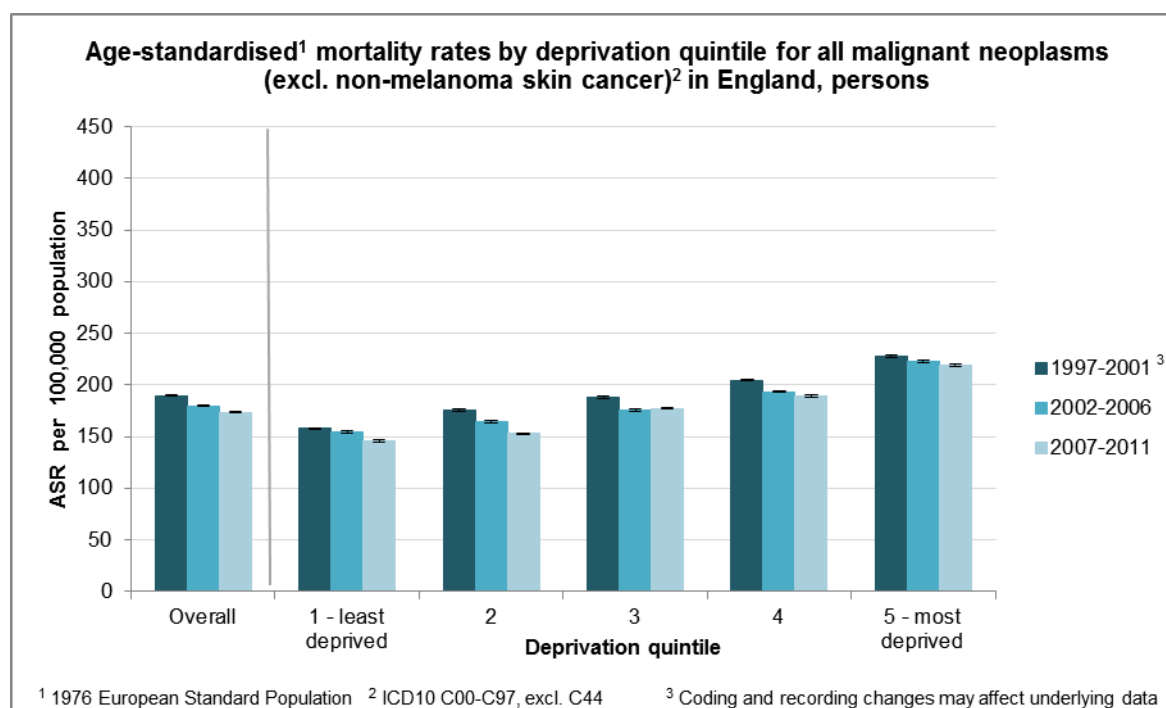
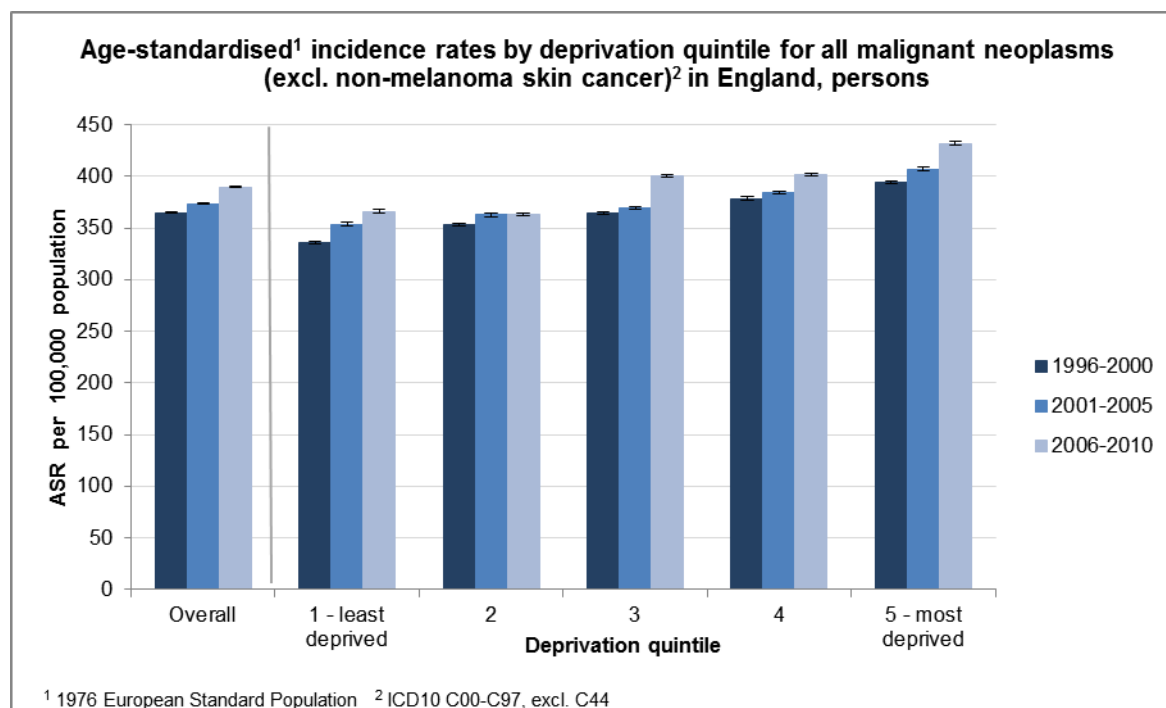


These data and further prevalence analysis by Strategic Clinical Network and deprivation and for the UK and UK constituent countries are on the NCIN website <http://www.ncin.org.uk>. This analysis is for all malignant cancers combined excluding non-melanoma skin cancer (ICD-10 C00-C97, excluding C44). It is based on people diagnosed with cancer between 1991 and 2010. To ensure that people, rather than tumours, were counted, only the first diagnosed tumour in each person was included in the analysis. Anyone who died or left the country in the period, or were aged over 99 at diagnosis or over 105 at the end of 2010, were removed from the study. England was the country of residence at the time of diagnosis. The numbers in this analysis may not agree with those published elsewhere due to slight differences in methodologies, periods of observation, datasets, and rounding.

Source: The National Cancer Data Repository (NCDR); National Cancer Registration Service (NCRS) and National Cancer Intelligence Network (NCIN), accessed June 2013.

*The Macmillan-NCIN Work Plan is a joint initiative between Macmillan Cancer Support and the National Cancer Intelligence Network (NCIN) to improve the understanding of people currently living with and beyond cancer. You can read more about the Macmillan-NCIN Work Plan on the website link above.

Annex C – Breakdown of incidence and mortality for all malignancies combined by socio-economic deprivation



- Incidence of cancers in England has increased across the three time periods in each deprivation quintile.
- Mortality from cancers in England has fallen across the three time periods in each deprivation quintile.

2006-2010 incidence by deprivation quintile in England for all malignant neoplasms, excluding non-melanoma skin cancer
(C00-C97, excl.C44; persons; rates per 100,000 population; excess 5-year average)

Deprivation quintile	Cases	ASR ¹	Confidence interval (95%)	ASR ratio	Yearly excess cases
1-least deprived	258,916	366	(364.8 - 367.6)	1.00	0
2	281,166	363	(361.8 - 364.5)	0.99	-448
3	275,617	401	(399.2 - 402.2)	1.09	4,750
4	258,114	402	(400.3 - 403.4)	1.10	4,319
5-most deprived	232,970	432	(430.3 - 433.8)	1.18	6,662
Overall	1,306,783	389	(388.8 - 390.1)		15,283

¹ Age-standardised rate using 1976 European Standard Population

2007-2011 mortality by deprivation quintile in England for all malignant neoplasms, excluding non-melanoma skin cancer
(C00-C97, excl.C44; persons; rates per 100,000 population; excess 5-year average)

Deprivation quintile	Deaths	ASR ¹	Confidence interval (95%)	ASR ratio	Yearly excess deaths
1-least deprived	115,575	146	(144.9 - 146.6)	1.00	0
2	133,962	153	(152.3 - 153.9)	1.05	1,044
3	136,842	177	(176.4 - 178.3)	1.22	4,409
4	132,917	189	(188.1 - 190.1)	1.30	5,242
5-most deprived	124,149	219	(217.5 - 220.0)	1.50	7,409
Overall	643,445	174	(173.0 - 173.9)		18,105

¹ Age-standardised rate using 1976 European Standard Population

- For the latest time period of incidence data available (2006-2010) there were on average just over 260,000 new cases of cancer diagnosed each year in England.
- For the latest time period of mortality data available (2007-2011) there were on average just under 130,000 deaths from cancer each year in England.
- Compared to a situation where each deprivation quintile had the same incidence rate as the least deprived quintile, there were on average 15,283 excess cases of cancer diagnosed each year between 2006 and 2010. However, this was not evenly distributed across the deprivation quintiles. In quintile 2 there was a 'negative excess' of -448 cases per year on average, meaning the actual number of cases was lower than expected in this quintile. It is well known that for some cancer types (e.g. lung cancer) incidence increases with deprivation, while in others (e.g. breast cancer) it decreases with increasing deprivation. In the most recent period (2006-2010), the offset from this, results in the lowest all-cancer incidence rate in quintile 2. In quintiles 3 and 4 there were 4,750 and 4,319 excess cases per year while in the most deprived quintile there were 6,662.
- Compared to a situation where each deprivation quintile had the same mortality as the least deprived quintile, there were on average 18,105 excess deaths from cancer each year from 2007 to 2011. Excess deaths increased as deprivation increased, with 1,044; 4,409; and 5,242 excess deaths per year in quintiles 2 to 4 respectively. In the most deprived quintile there were 7,409 excess deaths on average per year.

Annex D - NCIN analyses published October 2012 to October 2013

Publication Type	Title	Publication Date
Data Briefing	Incidence and survival of ampulla of vater and duodenal cancers	October 2012
Data Briefing	Recent trends in resection rates among non-small cell lung cancer patients in England	October 2012
Data Briefing	Bone sarcoma: Incidence and survival rates in England	October 2012
Report	One year relative survival rates for patients diagnosed with cancer of the oesophagus, stomach, primary liver, gallbladder, biliary tract and pancreas in England, 1985-2009	October 2012
Journal Publication	Hospital volume, proportion resected and mortality from oesophageal and gastric cancer: a population-based study in England, 2004–2008 – published in GUT	October 2012
Report	Rare urological cancers	October 2012
Report	Mortality from prostate cancer	October 2012
Report	Profile of cervical cancer in England: Incidence, mortality and survival	October 2012
Report	Bone sarcoma incidence and survival: Tumours diagnosed between 1985 and 2009	October 2012
Data Briefing	A profile of ovarian cancer in England	November 2012
Data Briefing	Variation in incidence of oesophageal and gastric cancers between ethnic groups	November 2012
Data Briefing	Variation in incidence of oesophageal cancer subgroups between ethnic groups in England	November 2012
Report	Overview of ovarian cancer in England: Incidence, mortality and survival	November 2012
Report	Haematological malignancies and cancer	November 2012

	registration in England (2004-2008)	
Data Briefing	Time from final surgery to radiotherapy for screen-detected breast cancers	November 2012
Journal Publication	Primary liver cancer incidence and survival in ethnic groups in England, 2001–2007 – published in Cancer Epidemiology	November 2012
Data Briefing	Thyroid cancer – trends by sex, age and histological type	December 2012
Data Briefing	Variation in incidence of primary liver cancer between ethnic groups, 2001-2007	December 2012
Report	Haematological malignancies in England: Cancers diagnosed 2001-2008	December 2012
Journal Publication	Cancer recording and mortality in the General Practice Research Database and linked cancer registries. Published in Pharmacoepidemiology Drug Safety	December 2012
Journal Publication	Population-based study of laparoscopic colorectal cancer surgery 2006–2008. Published in the British Journal of Surgery	January 2013
Journal Publication	Early mortality from colorectal cancer in England: a retrospective observational study of the factors associated with death in the first year after diagnosis. Published in the British Journal of Cancer	January 2013
Data Briefing	Liposarcoma: incidence and survival rates in England	January 2013
Report	Data quality for upper gastrointestinal cancer	January 2013
Report	Shared care and survival from childhood cancer in the UK 1997-2009	January 2013
Report	Soft tissue sarcoma incidence and survival: Tumours diagnosed in England between 1985 and 2009	January 2013
Report	Cancer outcomes in UK Biobank	January 2013

Report	Endoprosthesis replacement in surgical treatment of sarcoma patients – an audit of EPR surgery recorded in HES data compared with a specialist sarcoma centre database 2000-2009	January 2013
Data Briefing	Short term survival of children with cancer	February 2013
Data Briefing	Short term survival for teenagers and young adults: 2005-2009	February 2013
Journal Publication	Measures of promptness of cancer diagnosis in primary care: secondary analysis of national audit data on patients with 18 common and rarer cancers. Published in British Journal of Cancer	February 2013
Report	Baseline assessment of sentinel lymph node biopsy practice across England for malignant and melanoma patients	February 2013
Report	Outcomes in leukaemia: Trends in five year survival between 1995 and 2003	February 2013
Report	Diverging trends in lung cancer survival between males and females	February 2013
Report	Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010	April 2013
Journal Publication	Prognosis is deteriorating for upper tract urothelial cancer: data for England 1985–2010 – published in the BJU International	March 2013
Journal Publication	A retrospective observational study of the relationship between family history and survival from colorectal cancer – published in the British Journal of Cancer	March 2013
Report	Data Quality Report 2013 National Cancer Data Repository 2010 Data - Skin Cancer SSCRG	April 2013
Report	Lung Cancer and Mesothelioma Site Specific Clinical Reference Group Data Quality Report 2009	April 2013
Report	National Registry of Childhood Tumours	April 2013

	Progress Report, 2012	
Data Briefing	Short Term Ovarian Cancer Mortality	April 2013
Report	Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England	May 2013
Report	Routes to diagnosis: investigating the different pathways for cancer referrals in England for Teenagers and Young Adults	May 2013
Report	Frequency of non-specific morphology codes (ICD-O M) within the National Cancer Data Repository (2007-09) for cancer in Teenagers and Young Adults (TYA)	May 2013
Data Briefing	Routes to diagnosis: Exploring emergency presentations	May 2013
Report	What cancer statistics are available, and where can I find them?	June 2013
Report	Investigation of potential indicators of co-morbidity on outcomes for children with leukaemia using linked Hospital Episode Statistics data	June 2013
Report	Cancer and Equality groups: Key metrics	June 2013
Data Briefing	Routes to Diagnosis: Comparing multiple studies	June 2013
Data Briefing	Registration for Blood Cancers in England: comparison of routine data with a specialist population-based register	June 2013
Data Briefing	Non-melanoma skin cancer in England, Scotland, Northern Ireland and Ireland	June 2013
Journal Publication	Gender inequalities in the promptness of diagnosis of bladder and renal cancer after symptomatic presentation: evidence from secondary analysis of an English primary care audit survey – published in the British Medical Journal	June 2013
Report	Penile Cancer Report: Malignant and In-Situ Tumours	July 2013
Report	Radiotherapy treatment in DAHNO 2010/11 -	July 2013

	National Head & Neck Cancer	
Report	Simplifying the measurement of co-morbidities and their influence on chemotherapy toxicity	July 2013
Report	Bone and Soft Tissue Sarcomas UK Incidence and Survival: 1996 to 2010	July 2013
Data Briefing	Astrocytic brain tumours: survival rates in England	July 2013
Journal Publication	Falling bladder cancer incidence from 1990 to 2009 is not producing universal mortality improvements – published in the Journal of Clinical Urology	July 2013
Data Briefing	Ependymal tumours of the brain and spinal cord: survival rates in England	July 2013
Journal Publication	Recent childbirth is an adverse prognostic factor in breast cancer and melanoma, but not in Hodgkin lymphoma – published in the European Journal of Cancer	August 2013
Report	Data quality and completeness report: 2010 registrations for head and neck cancer	September 2013
Report	Blood cancers data quality report	September 2013
Report	Estimated completeness of ascertainment for childhood cancer in the UK, 2005-2010	September 2013
Journal Publication	Emergency presentation of cancer and short-term mortality. Published in the British Journal of Cancer	September 2013
Data Briefing	Uterine cancer in the UK: Overall trends and variation by age	October 2013
Report	Outline of uterine cancer in the UK: Incidence, mortality and survival	October 2013